NHS Gloucestershire

end of life care

End of Life Care

Everyone's business in Gloucestershire

January 2010 *Issue 7*

Welcome to the seventh 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.

In this issue:

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.

Liverpool Care Pathway in the National Press

The National Marie Curie Palliative Care Institute which developed the LCP has responded with a statement in light of these new media stories. This has been published on the Institute website **www.mcpcil.org.uk**

The National LCP Team has 10 key messages about the LCP:

1. The LCP is only as good as the person using it
2. LCP should not be used without education
3. Good communication is essential
4. LCP neither hastens nor postpones death
5. Diagnosis of dying should be made by MDT
6. LCP does not recommend the use of continuous sleep sedation
7. LCP does not preclude the use of artificial hydration
8. Continual reassessment is important
9. Reflect, audit, measure,learn Stop, think assess & change
10. Stop, think assess & change

"A bad death should no longer be acceptable."

"Dying is not just a medical issue, it is a societal issue"

Professor John Ellershaw, Lead of MCPIL

For more information

http://www.agooddeath.co.uk/

For a more comprehensive update on national end of life care news go to **http://www.endoflifecareforadults.nhs.uk/eolc/files/NHS-EoLC_News_Update_15_Aug2009.pdf**

NHS South West

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.

Latest update

EOLC Adastra Register

The Pilot continues in North Somerset and Bristol. The new edited version went 'live' before Christmas and a template to support the implementation process have been developed. Dr Simon Smith is leading on this piece of work so more details please contact Simon Smith on **Simon.Smith3@glos.nhs.uk**

Further updates will follow

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:

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

Education & training

Each PCT is concentrating on developing an Education Pathway that will underpin EoLC tools and support generalists in the delivery of care. Refer to page 4 to see how Gloucestershire's plan is developing.

A response to the LCP media debate

This piece is written in response to the letter discussed widely in the media at the beginning of September regarding the increasing use of the Liverpool Care Pathway in the management of patients reaching the end of their lives. Although there is little robust evidence to show that the quality of patient care is improved by the use of the pathway, it is becoming seen as the standard for care of dying patients in all settings.

The article, available online on the Daily Telegraph website for 03/09/2009, raises concerns about the use of the LCP becoming a self-fulfilling prophecy : stop regular medication, withdraw artificial nutrition and hydration then the patient will surely go on to die. It also raises the possibility of patients dying on continuous sedation which may be completely inappropriate, masking signs of improvement, following spells of agitation that may be secondary to dehydration or the use of analgesia.

One of the many concerns is that ' it is tickbox medicine that stops people thinking'.

Whilst all opportunities to openly discuss the care of dying people are welcome, the tone of the letter was such that it was open to media interpretation and sound bites that detracted from – or completely obliterated – many of the broader points it was making. I would agree with the authors that a dying patient, on a pathway or not, needs regular, scrupulous review, receiving the highest standards of medical and nursing care. I would share the concern that, once a person's care is contained and directed by the Liverpool Care pathway, there is a risk that healthcare professionals stop thinking and tickboxes.

However, the LCP does not order that all medication is stopped. Nor is its use synonymous with routine, unthinking, continuous sedation. It simply asks healthcare professionals to review the person's medication in the light of their deteriorating situation, thinking carefully about benefits versus burdens of treatment in a person who could be entering the last days of their life. If there is any doubt, then it is perfectly reasonable to continue medications on the drug chart within the pathway. It merely asks the healthcare professional to think about medication rather than continue blindly on, it does nor ban routine medication if it is felt to still be appropriate. An example of this not being followed is that of a patient whose arthritic pain was well controlled with regular Paracetamol. On commencement of the LCP, the patient's relatives were told that one cannot have Paracetamol for pain, one has diamorphine. This was completely inappropriate.

The LCP will not prevent the patient from improving – indeed, in one recent case, the cessation of the patients' usual medication saved his life as his condition improved and LCP was therefore reviewed and deemed inappropriate. There are no orders for continuous sedation. There are prescriptions for low doses of anxiolytic, analgesia, antiemetic and anti-secretory drugs that are there to prevent a person in need having to wait for a prescriber. In the setting of community hospitals and at home, this wait may be hours. The 'as required' nature of the prescription means that the patient receives what he / she needs, when he /she needs it. To prescribe a syringe driver requires review of the patient and a thoughtful process of considering the patient's symptomatic needs and how best they can be met.

This needs to be a larger and more detailed discussion. In summary, as Gloucestershire Hospitals Foundation Trust prepares to change documentation from the home grown care pathway in use, to come in line with the UK-wide version now in use in the community and community hospitals across the county, the following points need to be made:

- that a patient, being cared for on the Liverpool Care pathway or not, should receive careful review in their last days, and should not be subjected to tick-box, unthinking healthcare
- that it is perfectly acceptable to come off the pathway if the situation changes
- that the pathway's goals of improving communication, reviewing the value of investigations and medications in this individual's circumstances, and anticipatory prescribing of low dose

Continued on page 4

End of Life Care in Gloucestershire

- as required medication, are a step along the way to improving the quality of care we provide to patients who may be entering the last days of their life

Having read the very troubling blogs that followed the publication of the article in The Daily Telegraph on 3rd September 2009, we all clearly have a lot more work to do in improving the care of patients in our hospitals, nursing homes and at home. The correct and thoughtful use of the Liverpool Care Pathway may be one way to start this work and its goals listed above are to be lauded.

Dr Cath Blinman, Consultant in Palliative Medicine, Cheltenham General Hospital

New Post: County-wide Education Post

Sue Goold has just been appointed as County-wide Education Post. This is part of EoLC Education Strategy to facilitate and establish sustainable and long term solutions for the training, education and support of care providers delivering End of Life Care in Gloucestershire.

Sue's role will be to **co-ordinate** and **lead** on a multi-disciplinary training curriculum for generalists based on Skills for Health and Care Core competencies for professionals working with adults in EoLC. She will be working closely with the EoL Education Steering Group to coordinate Education Programmes. One of her main priorities will be to link in with wider local and national training agendas, particularly linked to the improvement of quality care, which is a core outcome of the National EoLC Strategy.

Sue will be building on existing work streams such as the PCT Mandatory EoLC Study day (see page 16 for details) and the development of Education Packages on Bereavement, Raising Awareness, Communication Skills and Advance Care Planning.

End of Life Care Facilitators

Karen English covers **Cheltenham, Tewkesbury, North** and **South Cotswolds**. Karen works on Mondays, Tuesdays and Wednesdays. (Karen will be on maternity leave from 10th March)

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

Gina King covers the **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**

Community Steps

In collaboration with the Gloucestershire County Council Education Department, all Home Support Officers from the Community Steps Team have been trained during November to train their Home Support Workers in how to use the LCP within their role.

It has already been demonstrated that it can 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.

Contact: **pat.williams@glos.gov.uk** or **Karen.english@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.**

Updates for Gloucestershire

End of Life Steering Group

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

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 8th March 2010

Community Specialist Palliative Care

The Gloucestershire survivorship project went live at the beginning on November 2009. This pilot project is a new way of following up patients living with and beyond cancer in the community using an existing resource (Village Agents) to signpost cancer survivors to the most appropriate advice/professional. It is hoped that this will help improve the patient experience and ensure more timely access to advice. This in turn might result in earlier return to work, reduce admissions and improve the quality of life for cancer survivors. All adult cancer survivors, their carers and family living in the county, will be able to access the agents. Patient leaflets explaining the service and further information can be obtained through project managers **Sarah Dryden/Fran Callen** on **08454 228118**.

This project is a perfect example of collaborative working involving cancer patients and carers, employees from the 3 Counties Cancer Network, Gloucestershire Hospitals NHS Foundation Trust, Gloucestershire Community and Adult Care, Gloucestershire Rural Community Council and Macmillan Cancer Support all working together to support cancer survivors.

Debra Clark Clinical Nurse Manager/Modern Matron (Macmillan) Tel **01452-371252**

Liverpool Care Pathway for the Dying (LCP) county-wide

Hospitals

Gloucester Royal Hospital and Cheltenham General Hospital have changed their documentation from the Integrated Care Pathway to the Liverpool Care Pathway on 16th November 2009.

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.

Contact: **helen.roberts@glos.nhs.uk** or **ann.barr@glos.nhs.uk**

Local Service Updates

²gether Trust

Current work streams are underway in the following areas:

- Training and Education
- Identifying leads and champions;
- Links and access to generic EoLC training;
- Development of Care Pathway approaches i.e. the Liverpool Care Pathway and Advanced Care Planning;
- Development of supporting protocols including roles and responsibilities of staff to meet the quality markers
- Critical Incidents- learning from live issues and problems;
- Service user involvement (focus group work).

Leads are appointed who are tasked with working on each area of the action plan. Programmes of work have just begun so progress is in early stages however there has been early positive development in training for those with a Learning Disability and Dementia.

Gloucester Royal Hospital Foundation Trust

The Acute Trust has an EOLC Steering Group led by Dr Janet Ropner (Assistant Medical Director). All sub-groups will feedback their progress at the next meeting in March.

- "Discharge Home to Die" (Trust Documentation) group has formulated a report to the Steering group
- Sam Guglani leads on Diagnosing Dying and the Oncology wards are piloting "The Unwell/Deteriorating Patient Management Plan" This looks at the plan of care and whether the patient should be transferred to Critical Care in the event of deterioration and whether they should be for resuscitation or not.
- The Bereavement Care Group is planning transfer of their GRH ITU Bereavement follow up service to CGH see page 16 for details.
- Sue Manser has included End of Life issues and difficult questions in the existing training for all groups of non-medical staff. Dr Cath Blinman is working with the Medical Staff.
- Dr Cath Morrison is leading on Advance Care Planning and will report to the next Steering group. She links in with the ACP Pilot in Care Homes

NHS Gloucestershire Care Services

- A locality model for EOLC will be scoped by a working group in January 2010.
- Work continues relating to Continuing Health Care and streamlining an EOL pathway.
- New documentation (FACE) for District Nurses has now been implemented. This should improve consistent record-keeping and will be the first documentation to include documentation of the patient's preferred place of death.
- Work is in progress on IV therapy by Marilyn Sheppard which has resulted in the development of policies and check lists to be used in conjunction with care plans.

Update on Progress of the Advanced Care Planning Pilot in Care Homes in Stroud by Dr Sarah Atherton

"How people die remains in the memory of those who live on" - Dame Cicely Saunders

Back in the autumn I was asked by the practice based commissioning group in Stroud to take the role of GP lead for a project promoting high level end of life/advance care planning. Following on from the national End of Life Care Strategy the PCT commissioned the Stroud locality to identify five Care Homes that could take part in the project. The aim has been for the five Homes to become "Beacons" in best practice, the knowledge learned then to be disseminated countywide.

The project has an aim of **enabling residents to die with dignity at their preferred place**. For most this means not in hospital. Often a small amount of pre-planning can avoid unnecessary admissions. The contribution to the project has been multidisciplinary. I have been acting as a liaison with the care homes, the OOH service, other GP's, and the PCT. One of my main functions has been to promote good communication with the care homes and primary care. For example it has been encouraged that all the care homes have an up to date medical summary on residents. This can make a real difference to decision making during out of hours periods when GP records are not available. I work for the Out of hours service also and know first hand that the more knowledge I have when visiting a patient I have never met before makes an enormous difference as to whether to admit or not. Care homes and GP's liaising more frequently, especially regarding potentially foreseeable problems could make a real difference. A "crisis" at 3am in the morning can then hopefully be managed with more confidence. If the OOH team does then become involved they are also given a greater degree of information as to the patients and relatives wishes.

The project is still underway.

The ideals and the reality of reaching all our aims has always been a challenge for those working within the NHS and other care services. The pressure of time and volume of work puts up many obstacles but striving for improvement is a worthy goal. Hopefully this project covering a small area will in time have a beneficial effect throughout the county.

Dr Sarah Atherton Locking Hill Surgery

Dr Sarah Atherton is the G.P lead supporting the GP Service Level Agreement pilot commissioned by the Stroud Practice Based Commissioning Cluster, for enhanced care for residents within Care Homes and piloted in the following within the Stroud Locality:

1. **Church Court, Stroud**
2. **Horsfall House, Minchinhampton**
3. **Moreton Hill, Stonehouse**
4. **Resthaven, Pitchcombe**
5. **The Hollies, Dursley**

Contact: **Maggie.martin@glos.nhs.uk** for further information.

Updates for Gloucestershire

Care Homes Pilot

The following care homes completed a pilot on the 11th January to implement the LCP in their care homes:

- Brunswick House, Gloucester
- Cleeve Hill, Cheltenham
- Hazlehurst, Forest of Dean
- Moreton Hill , Stroud
- The Grange, Stroud
- Hyperion House, Cotswolds
- Mill House, Cotswolds

Out of the 7 homes remaining in the pilot five homes have used the LCP for their dying residents. The two homes where the LCP has not been used have not had any deaths during the pilot period.

The feedback so far has been positive, as the document reduces the need for lots of paperwork consolidating the care required and ensuring that the care given has been documented. The pilot has highlighted the need for more medical support for the care homes using the LCP and also an issue regarding the availability of syringe drivers.

The next stage will be to roll out to other interested Care Homes in a staged process to ensure county-wide documentation.

Contact Maggie Martin on **07824 837201** or **Maggie.martin@glos.nhs.uk** for further details.

Facilitator Focus

As part of the conference there will a particular focus on service provision for certain diagnoses at End of Life highlighting three key issues: Rapid Access to Care, Coordination of Care and Raising Public Awareness. Leading professionals in these clinical fields have summarised as follows to support the day.

End of Life Care Conference

"One chance to get it right" - Working together towards excellence for everyone in End of Life Care

Thursday 4th February 2010

The Cheltenham Chase Hotel, Gloucestershire

Heart Failure Service and End of Life Care

Annie MacCallum
Head of Cardiovascular Services

Heart Failure is a progressive syndrome which in the later stages, is associated with symptoms which are increasingly difficult to control, frequent hospital admissions, failure by clinicians to recognise the palliative phase and a high association with sudden death even towards the end of life. The introduction of evidence based treatments have delayed disease progression and empowered patients and carers to become more involved in care and devices such as Biventricular pacemakers and Intra Cardiac Defibrillators are improving symptoms and reducing the incidence of sudden death, even in advanced disease.

The Countywide Heart Failure Service will become involved at any point in the patients care when the specialist intervention of this team is needed. Some of our patients return to our service many times, towards the end of life our links with Specialist Palliative Care and access to the inpatient facilities at Sue Ryder Hospice have helped us to help our patients achieve their preferred place of care at the end of their lives. Working with Sue Ryder, Cotswold Care and Great Oaks Hospices we have heart failure nurses seeing patients in clinic settings within the hospices. We are currently undertaking a pilot 12 week programme with Sue Ryder called ‘ Heart Balance’ which offers patients approaching the last phase of their lives, a chance to meet others, use the hospice facilities, learn relaxation techniques and see a palliative care clinician or counsellor if they wish. Early evaluation confirms it is very popular. We work closely with our primary care colleagues to support and advise when heart failure patients are choosing to die at home.

Raising Public Awareness

Cardiovascular disease (CVD) accounts for more deaths per annum in the UK than Cancer. 60,000 of these are attributed to heart failure alone, yet the public perception of death from CVD is associated with death from heart attack not from the long term consequences of CVD and Diabetes. The Heart Failure Service works with the British Heart Foundation in campaigns to raise awareness about the lack of provision of end of life services for people with heart disease and our nurses speak to CHD local support groups and work collaboratively with our palliative care colleagues to highlight the palliative needs of this group of people. The Head of Service is part of the national policy group of the National Council for Palliative Care addressing End of Life issues for people with heart failure.

Rapid Access to Care

The Heart Failure Service can be contacted by telephone, fax or letter. The service is open from 9am -5pm Mon-Fri. The telephone number 08454 221212 is a single point of access for both patients and clinicians. The service will respond in whatever timescale is needed based on patient symptoms.

Coordination of Care

Based in primary care the Heart Failure Service will accept any Gloucestershire patient meeting the criteria for this service from any source. The service can offer remote monitoring via Telehealth for up to 60 patients providing reassurance to patients and the ability to respond promptly to any change in condition. The Heart Failure Team will manage symptoms, provide support and liaise with clinical and social support agencies, out of hours services, primary care teams and specialist palliative care if necessary to provide effective palliative support to help patients maintain quality to their lives whilst achieving a preferred place of care. The experience of this service shows where possible, patients predominantly wish to die at home.

Developments in 2010

The service will evaluate the ‘Heart Balance’ programme, is collaborating with GHFT to facilitate early discharge of heart failure patients requiring palliative support utilising Telehealth more. Our specialist nurses are studying for a post graduate qualification in Advanced Heart Failure and Palliative management, more team members will attend an advanced communication course to help understand how to talk to patients about difficult issues. One of our team is attaining a post graduate qualification in Palliative Care, this in turn will advance the skills of the whole team.

Stroke and End of Life Care

What is a stroke?

Stroke, the brain equivalent of a heart attack, is caused by an interruption to the blood supply to the brain. There are two main types: ischaemic (where, for example, a blood clot can narrow or block a blood vessel) and haemorrhagic (where a burst blood vessel causes bleeding to the brain).

Who does it affect?

Most people who have a stroke are aged over 55, but men or women of any age can be affected. Some ethnic minority groups have increased levels of stroke and are affected at a younger age. Every year, an estimated 150,000 people in the United Kingdom have a stroke. Stroke is the third most common cause of death in the UK. Of all the people who have a stroke, about one third are likely to die within the first 10 days. This is usually due to severe brain injury damaging those parts of the brain that control breathing and the functioning of major organs.

Stroke is a medical emergency

For many years stroke has been seen as untreatable and as an inevitable part of ageing. However, the increased use of thrombolysis and the development of acute stroke units have had a positive impact on stroke services.

Rapid access to care

Gloucestershire Hospitals Foundation Trust provides a thrombolysis service locally and has extended access to the service as part of the Avon Gloucestershire Wiltshire Somerset Stroke Network thrombolysis rota. The number of rapid access Transient Ischaemic Attack clinics has also been increased to enable those at high risk to be assessed and treated quickly. Having an agreed pathway in place with Great Western Ambulance Service and Primary Care ensures more people are being assessed and treated more quickly than ever before.

A FAST response to raising awareness

In February 2009 the Department of Health launched a three-year campaign to promote public awareness around stroke. The campaign informs the public about stroke and F.A.S.T a simple test to help people to recognise the signs of stroke and understand the importance of fast emergency treatment. F.A.S.T. - Face, Arm, Speech, Time to call 999. Local press releases supported the national campaign which saw a sustained increase in 999 calls for stroke like symptoms in Gloucestershire, meaning more people are being assessed and treated appropriately.

Coordination of care

Within Gloucestershire there are two community based stroke coordinators. This service provides a person centered service of information, emotional support and practical advice to people affected by stroke, their families and carers. The community stroke coordinator liaises with colleagues across health, social care and local voluntary/support groups to ensure a seamless transfer of care from acute services into the community, ensuring a range of services are in place and easily accessible to support individuals, families and carers.

Considerations in End of life Care for stroke

Care of the patient after stroke can be complex, requiring support with any or all of the following:

- Positioning
- Pain – including shoulder pain and subluxation; neuropathic pain (central post-stroke pain) and musculo-skeletal pain.
- Depression
- Anxiety
- Communication
- Mental capacity (decision making by the patient)
- Bowel and bladder impairment
- Swallowing problems: assessment and management
- Nutrition
- Cognition
- Oral health

This brings together a number of unique problems in planning therapeutic end of life care that will need to involve family, carers, multi disciplinary teams and organisations.

The Royal College of Physicians stroke guidelines recommend that:

- Teams providing care for patients after stroke should be taught how to recognise patients who might benefit from palliative care.
- All staff caring for people dying with a stroke should be trained in the principles and practice of palliative care.

The challenge is to identify how, given the complexities, quality of care at the end of life can be improved for stroke patients.

Dementia and EoLC

Dementia is a chronic progressive neurodegenerative illness which has a terminal outcome over an average of 3 to 8 years. It brings a number of unique problems to planning therapeutic end of life care that need to be taken into consideration, quite apart from understanding the enormous, growing impact of dementia to the population and economy.

- People with dementia have a 4 to 6 times greater mortality rate than people cognitively intact
- 60% of older people admitted to hospitals develop a mental health disorder (MHD). MHD is a significant indicator of poor outcomes and increased mortality 1
- People with dementia have poor access to a range of services, including intermediate care, hospices
- Carers of people with dementia report that the individual was either often in pain or in pain all the time. Pain assessment tools need to accommodate memory loss, receptive or expressive dysphasia 2
- Older people with dementia often have other medical problems that make assessment of mental capacity a challenging, but fundamental step in Advanced care Planning 3
- Carers of people with dementia receive less support
- Limited workforce uptake of available dementia training

The National Dementia Strategy (NDS) published in 2009 4 identified the need to address the quality of end of life care for people with dementia. Objective 12 states:

Improved end of life care for people with dementia.

People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy.

The Gloucestershire response to the NDS has been outlined in the Gloucestershire National Dementia Strategy Action Plan, the key element is to work collaboratively with other strategies such as End of Life, Stroke, and Long Term Conditions. In Gloucestershire the NDS and the End of Life Care Strategy teams are working jointly to ensure that commissioners and providers include best practice in planning health and social care services that are responsive, appropriate, high quality and accessible.

For example;

- Public awareness of dementia is being stimulated nationally. A part time Communications Manager has just appointed to support Older People services, allowing a local response in line with the national media campaign that will start in January 2010
- The South West SHA Review of Dementia Services has recognised the joint Gloucestershire Dementia Training and Education Strategy as innovative and best practice. The training offers a range of options and media from basic awareness to an accredited qualification as a Dementia Link Worker. This approach has worked particularly well in care homes in 2009/10, with the focus shifting to community hospitals in 2010/11
- The Primary Care Dementia Pathway has just reached the end of its consultation phase. The South West Dementia Partnership has published the pathway on their website as an example of good practice in raising awareness in GPs. The pathway seeks to raise dementia in primary care and introduce the concept that it is a journey for the individual and carer and primary care practitioners, from early diagnosis to end of life.
- The Alzheimer's Society's Counting the Cost; caring for people with dementia on hospital wards has raised concerns about the care of patients with dementia in hospitals. The Gloucestershire NDS Action Plan is working closely with acute and community hospitals to look at a range of issues. Adequate assessment of pain relief is a challenge to both NDS and End of Life strategies. It is hoped that collaborative working will offer clinicians the appropriate skills to make a difference.

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For further information, contact:

Helen Vaughan
Commissioning Development Manager for Dementia Services
helen.vaughan@glos.nhs.uk
08454 221947

EoLC Conference Key Objectives

Respiratory and End of Life Care

Respiratory Care and End of Life Care

The Community Respiratory Team (CRT) offers a service around the county and is based in Edward Jenner Court. Our aim is to support patients, carers and Health Care Professionals (HCP) in the care of the respiratory ill. The majority of our work is around COPD but other long term respiratory conditions such as Asthma, Bronchiectasis, fibrotic lung diseases, tracheostomy, laryngectomy and non-invasively ventilated patients are also cared for by the team. Many of these diseases are incurable and our aims are to stabilise and control the symptoms; this is particularly so in the end of life care of the respiratory ill person.

Raising Public Awareness

Our role is to ensure HCP know of our skills in caring for someone at the end of their life. We now have greater links with the local hospices but are striving to raise our profile with Community Nursing, GPs and hospital teams who are often at the centre of the patients at most need of our expertise. We have close links with the British Lung Foundation (BLF) and their patients support Group BreathEasy and we have set up 2 groups with one to follow in the Forest of Dean in 2010; these groups support other suffers and raise awareness of the problems lung diseases have on the individual. Next year we will be working with the BLF to celebrate their 25th Anniversary which will help highlight the plight of the respiratory ill person. The CRT now has an intranet page which provides respiratory information and local events.

http://nww.glospct.nhs.uk/C16/Specialist%20Nurses/default.aspx

Rapid Access to Care

The Team offers an urgent referral service where patients are seen within 72 working hours of referral, but often the response can be the same day. Here we can offer help in symptom management, diagnosing and assessing hypoxia and getting supplemental oxygen into the patients' home urgently.

Coordination of Care

The team can quickly involve the services of other specialist teams such as the Heart Failure, District Nursing, Hospices and Social Care and can get added support from Hospital Specialist teams when expert advice is required. The Gloucestershire Respiratory Steering Group is currently working on the COPD pathway which will help in signposting patients early to the most appropriate care they need.

Improvements to the Service for 2010

So what is it that needs to be done that is not happening so far? Often we are called into assess the patient rather late in the disease trajectory and we feel we could offer many remedies for breathlessness and anxiety much earlier. This is often due to the disease presenting as unclear or variable in severity of symptoms but also highlights the continuing problems clinicians have in discussing and planning end of life issues. Urgent referral into the service relies on using telephone referral rather than using other routes which may delay the response needed. In 2010 we aim to improve our service offered to the palliative and dying person but this relies heavily in knowing who those people are and so we all need to look at the way we work and who we engage with to achieve the best care for our dying patients.

Kathy Cambell

Respiratory Specialist Practitioner, Community

Sharing excellence in EOLC in Gloucestershire

end of life care

National Award for Moreton Hill Care Home and Trish Pyne, Head of Care

Dee Lane, General Manager, Moreton Hill, is very proud of the team at Moreton Hill for winning the National Care Home of the year 2009 award. Of winning the Care Home of the Year Award, Dee said ‘ This award recognises everyone that contributes to the whole that makes Moreton Hill the caring home it is.’

Of Trish Pyne, who came second in the nurse finals, Dee states 'I am not surprised at Trish's success. Trish is a dedicated and professional nurse, the testimonies written by families detailed her attention to detail and passion for delivering person centred care, I am especially proud.'

Trish started out her nursing career as a nursing cadet and completed her Enrolled Nurse training in Preston. At 20 years of age she was the youngest District Nurse in Lancashire and following her marriage and birth of her daughter moved to Gloucestershire 25 years ago where she worked as a DN in Painswick.

Trish changed direction in her career and joined the independent sector and successfully completed her conversion course in 1994.

She has been working at Moreton Hill Care Home for the last 10 years as Head of Care.

Moreton Hill is taking part of the Liverpool Care Pathway for Care Homes and Advance Care Planning pilots.

The End of Life Care Team would like to offer their best wishes to Dee, Trish and all the team at Moreton Hill for winning the awards and look forward to continuing working with them in 2010.

Cotswold Care Hospice Education News….

Educating the patients and beyond…...

Cotswold Care Hospice Education Department is well known for delivering palliative care education to health and social care practitioners but now wants to extend the service to include patients, relatives or friends and then the public!

The first patient education session for patients was held recently when ex breast cancer patients learned about the risks of lymphoedema, what to look for and how to manage the situation if it arises. 12 people attended including one husband listened to the lymphoedema specialist nurses for the morning before enjoying a relaxed lunch in the bistro!

The evaluations were excellent encouraging us to plan further sessions for both patients and their relatives or friends.

The next patient and carer study session will be run by the Parkinson’s Disease Society Education team on May 18th 2010 from 2-4pm at Cotswold Care. If any patient or carer is interested in attending, they are asked to phone **Di Ponting** on **01453 733702** to book a place.

Department of Critical Care Bereavement Follow up Service

The idea of developing a bereavement follow up team first came about twelve years ago. A member of staff had a dentist appointment, in the waiting area they met the daughter of a man who had died suddenly in critical care following a road traffic collision. Although his death had been some eight years previous, his daughter still had numerous questions relating to his death, which had left her bewildered and unable to grieve properly. She did not know how or who to contact in order to address her questions.

As a result of this meeting a small group of nurses decided to formulate a follow up service providing level 1 bereavement care within critical care. Many means of providing this service were discussed, however it was decided the most straightforward and cost-effective method was offering relatives a telephone call.

Following a death the nurse asks the family if they would like a follow up call, this is documented with other relevant information on an audit form. The call is made 6 to 8 weeks after the death, 90% of the calls are very straightforward, how family members are, funerals are discussed and frequently appreciation towards the staff are expressed.

Only 10% of families require a second call, the main reasons are; understanding a PM report, a question for another provider, GP, other departments, wanting to speak with a consultant, another family member requires a phone call, signposting where further bereavement support can be found or a family member just wants to talk.

Following the second call if further help is required the nurse will signpost the family to the most appropriate support group or GP's. A card is sent to the family on the anniversary of the death simply saying "We are thinking of you on this day". The nurse documents the results of the telephone calls on the audit form; subsequently the forms are audited every six months providing valid information which is used to improve the service and to enhance our practice.

A simple, however very effective service, signposting, defusing issues, answering unanswered questions showing we have not forgotten and we care.

Jane Benfield
Senior Sister on behalf of the bereavement team; Critical Care Gloucestershire Hospitals NHS Trust Foundation

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/

3 Counties Cancer Network

3 Counties Cancer Network

The 3CCN newsletter introduces its new logo, launches its re-developed website, and includes information on NAEDI, LAEDI and the primary care audit; service improvement updates; peer review feedback; survivorship; information systems; the all-important staff updates and more.

http://www.the3ccancernet.org.uk/downloads/Newsletter%20December%202009%20final.pdf

The Community Nursing Newsletter

http://nww.glospct.nhs.uk/C6/C14/Newsletter/Document%20Library/DN_News4_231109.pdf

Specialist Palliative Care Out of Hours Advice for Professionals

5pm-9pm Monday to Friday

24 hours cover at weekends and bank holidays

PAGER: **07659 119458**

Sharing excellence in EOLC in Gloucestershire

Sue Goold, the education facilitator recently attended a 3 Counties Cancer Network user group and asked patients, carers and professionals what information/education is needed to help patients and the families with palliative care needs.

The following are just some of the suggestions that arose from both events.

Suggestions about Patient's needs.

- 'Knowing what might (or will) happen when I get worse. What problems can I expect'?
- 'What support is out there for us?'
- Meeting and talking with others that experience the same.
- How to gain access to a hospice
- 'How to manage pain – what available locally to help me?'
- 'How do I explain my condition to my family?'
- Psychosexual issues and how it affects cancer.
- 'Making a will, putting my house in order – speaking to a solicitor'
- Funeral arrangements – what options are there?

How can we help educate families/ relatives and the main carer'?

- Knowledge!!
- 'How to best keep the patient safe, happy and know how to cope and who to turn to when suddenly things get worse.'
- 'What support is there for the patient and ME?'
- 'How can I support the patient?'
- 'How do I relate to the patient? i.e. being strong, ignoring it, making light of the situation etc'
- What carer support groups are out there to help encourage each other
- 'How do I keep positive and re charge my batteries?'
- 'How do I deal with feeding her and her loss of appetite?'
- Carer days for us only and not the patient.

Cotswold Care plans to address some of these needs in 2010

Look out for the new website www.cotswoldcare.org.uk due in 2010 and click on the education page

If you have any ideas or want to help deliver any of the information we would love to hear from you.

Please contact Sue Goold 01453 886868 or email me on **sue.goold@cotswoldcare.org.uk**

A Temporary Farewell

We would like to congratulate Karen English who is expecting her second baby in April and wish her a fond but temporary farewell and we look forward to her return – she will be missed by the End of Life Team

All the best Karen!

Conferences, courses and study days

National Council of Palliative Care's forthcoming conferences:

http://www.ncpc.org.uk/events/asktheexperts.html

For End of Life Care related conferences:

http://www.endoflifecare.nhs.uk/eolc/event

RCN End of Life Care Roadshow -

2nd Febuary 2010
Broomsgrove Holiday Inn, Birmingham

Contact: Suzanne Sinclair
suzanne.sinclair@rcn.org.uk
020 7647 3581

"Achieving the end of life care pathway – what works?

The King's Fund, 11–13 Cavendish Square, London, W1G 0AN

17 March 2010

For further information:
http://www.kingsfund.org.uk

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.

End of Life Care – a case study approach

A Mandatory study day for Care Services on the knowledge and skills of the principles and procedures needed in EoLC.
Booking required via
LDPCT.Training@glos.nhs.uk

Dying Matters Awareness Week

15–19 March 2010
http://www.dyingmatters.org

Dignity in Action day

Find out in the resource pack by using the link below about ways you can make a difference in supporting Dignity in Action in Carein Day on 25th February.
http://www.dhcarenetworks.org.uk/_library/Resources/Dignity/DAD/Health_social_care_staff_Dignity_Action_Day_resource_pack.pdf
This would be a great opportunity for the health and social care community to promote initiatives around dignity in care across all sectors.

E-learning for end of life care

e-ELCA has been developed by DH e-Learning for Healthcare to support the implementation of the strategy.

Launched on 21 January 2010, e-ELCA offers easily-digestible e-learning sessions in four courses:

- Advance care planning
- Assessment
- Communication skills
- Symptom management

A fifth course integrates learning through case studies.

For more information visit
www.e-elca.org.uk or email
elca.support@e-lfh.org.uk

"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**