

SUFFOLK PALLIATIVE CARE

# spotlight

Issue 11 • Spring 2009

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## Welcome to the new look Spotlight!

As you can see we have a new look and a new editorial board. The board says goodbye and thank you to Jackie Saunders, who has been appointed to the role of Clinical Services Director at St Nicholas Hospice Care.

The editor role will now be shared between the editorial board, with the first issue being kindly edited by Yasmin Jeffery, the Marketing and PR Manager for St Nicholas Hospice Care.

The theme for this edition is the 'End of Life Care Strategy' which came out in July 2008.

We hope Spotlight will be useful to you and your colleagues. Please e-mail any feedback or comments to [madeline.bass@stnh.org.uk](mailto:madeline.bass@stnh.org.uk)

Many Thanks

**Maddy Bass, Head of Education,  
St Nicholas Hospice Care**

## OUT OF HOURS CARE

Take Care Now (TCN) is presently reviewing how it delivers palliative care out of hours. With the aim of providing a high quality and responsive service tailored around patient's individual needs and their end of life plans.

This will include having access to specialist palliative care advice, facilitating communication with a patient's own GP, liaising with palliative care teams, educating clinicians and call handlers and fast-tracking patients with palliative care needs within the system.

An administrator will communicate with surgeries on a weekly basis to update TCN's database. This will allow palliative care patients who access the service out of hours to be identified immediately so they can receive prompt, appropriate treatment and management consistent with providing high quality end of life care in the community.

**Please call Sally Gardner at Take Care Now on 01473 299622 for support and advice.**



*Acknowledgement that as a society we don't talk openly about death and dying.*

## END OF LIFE CARE STRATEGY: DRIVE UP PATIENT'S EXPECTATIONS

The End of Life Care Strategy 2008 is the first of its kind in the UK. Its central aim is to provide choice for adults approaching the end of life.

This strategy provides clear direction for both providers and commissioners of End of Life Care whilst generating an expectation of care for patients and families. End of Life Care has received a great deal of media attention recently and was one of eight key pathways selected by Lord Darzi in the next stage of the NHS review. This review had the ambition to drive up patient's expectation of services from 'safe' to 'quality'.

### Some of the specific challenges arising from the End of Life Care Strategy for healthcare professionals include:

- It is essential that people who are approaching the end of their life are identified and timely discussions are initiated about their preferences for care
- One template in which to capture and communicate peoples preferences is an 'Advanced Care Plan'
- Professionals must plan and evaluate care based on regular comprehensive needs assessments at significant events, i.e diagnosis, increasing dependency, change in care venue
- Ensure such care is coordinated across all services
- To acknowledge tertiary health promotion as one essential approach which may empower and enable patients and carers
- Recognise that the management of the last days of life can be enhanced utilising initiatives such as the Liverpool Care Pathway (LCP)
- Professionals must continue to be resource aware in order to provide support for families and carers both during a person's illness and life after death
- Acknowledgement that as a society we do not talk openly about death and dying.

Pursuing sensitive and innovative ways of encouraging dialogue will be fundamental towards meeting the challenges set by this strategy.

**Trevor Farrington, Head of St Nicholas Hospice Care Community Team.**

## THE END OF LIFE CARE:

### STRATEGY AND ACUTE HOSPITAL CARE

At present over half (58%) of all deaths occur in acute hospitals, changing this and giving patients a choice, will be challenging. The end of life principles of care planning, co-ordination of care, rapid access to care, involving and supporting carers and education and training, apply in hospitals as they do in all care settings. It can be difficult for hospital staff to recognise patients who may be approaching the end of their life and difficult for patients who no longer want active treatment to have their voices heard.

The acute hospitals have made great strides to improve the care of patients at the end of their lives over recent years. The End of Life Care Strategy raises the profile of a 'Cinderella' patient group and services. The Liverpool Care Pathway, now in use on all wards in Ipswich and the West Suffolk Hospitals, has transformed the care of the dying patient by providing a framework for ward

staff. Both hospitals are involved with the National Liverpool Care Pathway audit for hospitals, providing evidence of the pathway's use.

The challenges for the Trusts include providing appropriate support for families and carers in a culture where patient confidentiality is paramount. Timely and co-ordinated discharge requires staff with the vision to see care can be provided in a different way, together with detailed knowledge of the services available in the community. The co-ordination of patients' care is going to require improved communication and sharing of information.

Education and development of the hospital workforce will take time, as the majority of hospital staff is involved. More cancer clinicians are now trained in 'Advanced Communication Skills' but this will need to be rolled out for all patient groups. Equality of access to support and services will need to be monitored and addressed if we are going to get this right.

**Katie Williams, Clinical Nurse Specialist in Palliative Care, West Suffolk Hospital**

*The acute hospitals have made great strides to improve the care of patients at the end of their lives over recent years*

## END OF LIFE TRAINING FOR NURSING HOMES

'The Gold Standards Framework for Care Homes' has enabled us to develop our clinical skills and further improve the quality of care we already offer our residents.

Talking about death and dying with residents and their families can be difficult, but through the use of advanced care planning, we have opened channels for a more open communication regarding wishes on future treatment, resuscitation and preferred places to die.

The multi-professional support we now receive has made an enormous difference to our decision-making, taking into account that we do not have a doctor on site. Communication with Suffolk doctors has also improved through the use of the 'Out of Hours' forms.

The Hospice at Home service, provided by St Elizabeth Hospice, offers a twentyfourhour advice and support service, which has been extremely helpful dealing with questions such as symptom control and prescription queries.

Annette Willis, Head of Education at St Elizabeth Hospice previously supported and led us from the start of the programme. She has lead meetings with GP's and other care home staff to discuss and share ideas, offered in-house training and education on symptom control and on the use of syringe drivers.

The Liverpool Care Pathway has also been useful as it offers a checklist addressing all areas of end of life care and ensuring holistic care for the individual.

By anticipating our resident's needs at the end of life, and being proactive, the use of the 'Gold Standards Framework' has meant our residents wishes are being met and staff feel able to offer what everyone deserves – a good death.

**Claire Bridgeman, Training Co-ordinator, Sister Jacqui Davy and Senior Nurse Julie Moore**



Chilton Meadows  
Residential & Nursing Home



From left Claire Bridgeman, Training Co-ordinator and Senior Nurse Julie Moore

*Staff feel able to offer what everyone deserves – a good death*

## POSITIVE LIVING

The Positive Living programme at St Elizabeth Hospice is available to patients, relatives and carers, and aims to enable patients to live positively with their condition. The group concentrates on non-medical interventions for physical, psychological, social and spiritual support, through the giving and sharing of information about different coping strategies.

The course is structured toward education, promoting independence, relaxation and social interaction. It introduces the Hospice multi-professional team (HMPT) and their services, whilst providing an opportunity to meet others in a similar situation.

Each group has no more than twelve people, six patients and their carers. The course consists of six weekly one hour sessions and time for refreshments and a chat with other attendees.

Each session is dedicated to information sharing and education from a member of the HMPT addressing a specific topic including; energy conservation, anxiety and fatigue management, managing symptoms, complementary therapy, breathing techniques, exercise, diet, sleep and psychosocial support. Comments from attendees include: "We found the sessions very helpful. The people taking them were very kind and attentive."

### Supporting Documents

National Institute of Clinical Excellence (2004) Improving supportive and palliative care for adults with cancer – the guidance. National Institute of Clinical Excellence, London.

National Council for Hospice and Specialist Palliative Care Services (2006) Fulfilling Lives: rehabilitation in palliative care. 2nd ed. National Council for Hospice and Specialist Palliative Care Services, London.  
**Alicia Smith and Andrea Cook, St Elizabeth Hospice**

**Two Positive Living Programmes offered by St Nicholas Hospice Care are explained below.**

### Fatigue Management Group

Cancer related fatigue affects nearly 80% of all people with a cancer diagnosis. It is often overlooked by professionals and patients, as being a physiological symptom of their disease. Referrals to the group can be made from other Hospice clinical staff and from our colleagues in the community.

At St Nicholas Hospice Care we run the Fatigue Management Group three times a year. It runs for five weeks, on a Thursday between 12 noon and 2pm and caters for a maximum number of 12 people. Each week we discuss a different topic related to fatigue – sleep patterns, pacing, setting goals, nutrition, aromatherapy, making the most of your energy and relaxation.

On each occasion we have a gentle and tailored exercise circuit. The benefits of exercise in fatigue management are well researched, but often unexplained to sufferers. The benefit of exercise is demonstrated, by a walking test carried out on the first visit being compared with the same test on the final visit.

The group setting serves as a forum for the participants to share their experiences and we invite carers to attend the final session with the patients. A sense of fun and a light lunch is always present.

### Breathlessness Clinic

Breathlessness affects three quarters of patients diagnosed with any type of cancer and 90% of those with lung cancer.

At the Breathlessness Clinic we aim to give the patient a 'toolbox' of non-pharmacological techniques. This toolbox will contain breathing exercises, the breathing square, relaxation, positions of ease, and the use of a hand held fan. We also discuss pacing and prioritising of activities.

The clinic runs the second Tuesday of every month and patients attend once for a one and a half hour clinic. On each occasion the occupational therapist takes a relaxation session with the group. Patients attending then benefit from sharing their experience with the other participants and often have useful tips to share with each other.

**Sheona Fraser, St Nicholas Hospice Care**

## PHYSICAL CHANGES

### MODERNISATION – BACK TO BASICS AT ST NICHOLAS HOSPICE CARE

Last year the government encouraged Hospices to refurbish and improve their environments. St Nicholas Hospice Care decided to look at it from the patient and families perspective: what do dying and severely ill people want and need?

**A room with a view.** As people become bedbound or less able to walk, their view becomes their boundaries. We removed all the wooden dividers to the windows which allowed the glorious gardens to seem as if part of the Ward.

**Colour and light.** All the rooms have coordinated and restful themes, textures and colours.

**Dignity.** The rooms were redesigned to ensure space, accessibility to belongings and privacy. Curtains were improved, call buzzers became wireless, free-to-watch TV screens and bedside phones added. Two rooms now have space to allow family members to 'move-in' and to sleep alongside their loved one in comfort.

**Comfort.** The installation of air-conditioning and improved heating systems for year-round comfort. Electric recliner chairs and riser beds for all and lighting designed around the individual's needs, from reading lights to dim night lights.

**Safety.** Increased cupboard space to ensure storage of 'kit' is no longer in 'corners' and thereby reducing clutter and trip-hazards. The maximum use of wireless equipment and the design of bedhead space to accommodate sockets has minimised wires draped across the floors.

**Hygiene.** All carpets were replaced with beautiful coloured 'linoleum' flooring. This means less falls and trips and a much quicker deep clean process for the housekeeping staff. Non-touch taps throughout the clinical areas help reduce cross infection.

The result of the refurbishment project is a newly named 'Sylvan Ward' that has patients needs at its heart.

**Jackie Saunders, Clinical Services Director, St Nicholas Hospice Care**



*Small changes making a real difference.*

### New look day care services at St. Elizabeth Hospice

Day care services were one of the areas to benefit from the recent £1 million building project at St Elizabeth Hospice; creating additional space, allowing more services and more patients to access day care and providing more facilities for rehabilitation. The modernisation included internet and multimedia access for patients. More than one service in the day unit can be offered at the same time and it is better equipped for those with a complex disability. Patients can attend for a full day or half day.

Other services available include nurse-led clinics, medical out-patient clinics, group work, complementary therapies, positive living group, out-patient therapies, hearty living group, energy conservation clinic, creative therapies and lymphoedema services.

St Elizabeth Hospice plans to continue developing its range of services to ensure day care is responsive to changing needs in the East Suffolk community. The Hospice is looking at setting up support groups and more clinics, for example, a breathlessness clinic and an anxiety management clinic. The aim is to offer earlier interventions such as rehabilitation and offer more support to carers such as regular respite and a dedicated carers support group.

St Elizabeth Hospice plans to continue developing its range of services to ensure day care is responsive to changing needs in the East Suffolk community.

**Lesley Cockerton, Chief Executive, St Elizabeth Hospice**

## COLLABORATIVE EDUCATION: DELIVERING A CONSISTENT APPROACH

The demand for palliative and end of life care education has always been high; the publication of the End of Life Care Strategy highlights the need for further education and training. This provides an ideal opportunity to share resources and standardise education and training across Suffolk.

Annette Willis, Head of Education at St Elizabeth Hospice, and Madeline Bass, Head of Education at St Nicholas Hospice Care have been working together with other education colleagues with a goal to deliver palliative and end of life education to as many people as possible.

Annette and Maddy have worked in specialist palliative care for many years and can contribute their joint experience and knowledge to that of other professionals in Suffolk. They both have experience of specialist palliative care on a regional and national scale, and value the skills and knowledge that can be tapped into within the Suffolk community of healthcare professionals.

This collaboration started with a joint syringe driver study day; the two Hospices are now also working with Macmillan Cancer Support, Marie Curie Cancer Care and Ipswich Hospital Palliative Care Team on study days in early 2009.

"We know that education does not only occur in the classroom, and that it is becoming harder for healthcare professionals to attend education and training. We want to offer as much education as possible and are investigating other ways we and our colleagues can support local Health, Social and Allied Health professionals, such as e-learning and competency-based learning", commented Maddy.

In each edition of Spotlight, Annette and Maddy will highlight a list of local educational events and useful websites. See below for more details.

### Education events:

The list of topics and courses to be run either collaboratively with St Elizabeth Hospice and St Nicholas Hospice Care or independently in 2009 are listed right:



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[www.stelizabethhospice.org.uk](http://www.stelizabethhospice.org.uk)

alongside you  
when you  
need it most

**St Nicholas  
Hospice Care**

**email:** [www.stnicholashospice.org.uk](mailto:www.stnicholashospice.org.uk)

This newsletter provides an overview of examples of practice identified by Suffolk clinicians. The editorial board accepts no liability for any error or omission in the content material or outcome of use of the information. The views expressed in the articles are the contributor's own and do not necessarily reflect those of the editorial board.

### St Elizabeth Hospice and St Nicholas Hospice Care collaborative courses

- The Family Matters (collaborative)
- Dementia Study Day (collaborative)
- University Campus Suffolk "How to Manage End of Life Care" CPD day and repeated at St Nicholas Hospice Care on March 16 2009.

### St Elizabeth Hospice

- The Elephant in the Room
- Verification of Expected Death
- Advance Care Planning
- Syringe Drivers
- Palliative Care Emergencies
- DNACPR/Ethics
- Taking Care of Yourself
- Introduction to Palliative Care for HCA's
- The Sick Heart-Heart Failure 1
- The Sick Heart- End of Life 2
- Creativity its place in Palliative Care
- Talking to patients-changing practice
- The Challenges of Working with Loss, Grief and Bereavement
- The Art of Spiritual Care
- Symptom control in Palliative Care

### St Nicholas Hospice Care

- Adult bereavement: one day course, January 2009
- Children and Grief: four day course, February 2009
- Ethics in Palliative Care, April 2009
- Psychosexual issues in palliative care: two day course in 2009
- Essentials: free sessions on pertinent palliative care subjects.
- Palliative care forum: for community staff in West Suffolk, discussing relevant issues in palliative care: runs four times per year.
- Child bereavement forums: a supportive forum for anyone working with children affected by the death of someone close to them. Run four times per year.

### Ipswich & West Suffolk Palliative Care Team

- Non-malignant Palliative Care conference, 4th March 2009

More information can be found on the Hospice websites listed in the Editorial contacts.

## WEBSITES:

Advanced Decision to Refuse: [www.adrtnhs.co.uk](http://www.adrtnhs.co.uk)

East of England Strategic Health Authority: [www.eoe.nhs.uk](http://www.eoe.nhs.uk)

End of Life Care - NHS: [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

Information on GSF in the community and care homes: [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

Macmillan learning zone: <http://learnzone.macmillan.org.uk>

Marie Curie: <http://www.mariecurie.org.uk>

Palliative care policies and guidelines, research and audit information: <http://palliativedrugs.com>

Primary Care Trusts: [www.dh.gov.uk/en/Healthcare/Primarycare/Primarycaretrusts/](http://www.dh.gov.uk/en/Healthcare/Primarycare/Primarycaretrusts/)

St Nicholas Hospice Care: [www.stnicholashospice.org.uk](http://www.stnicholashospice.org.uk)

St Elizabeth Hospice: [www.stelizabethhospice.org.uk](http://www.stelizabethhospice.org.uk)

Suffolk New College: [www.suffolk.ac.uk](http://www.suffolk.ac.uk)

Syringe driver training, wound care training, on-line live lectures: <http://cancernursing.org>

### St Elizabeth Hospice patient DVD

St Elizabeth Hospice has produced a DVD entitled, 'A patient's guide to St Elizabeth Hospice'. The DVD aims to show patients and families the benefits of the range of services on offer, and to familiarise them with details such as the interior look and atmosphere of the Hospice. The DVD will also be helpful, as a training tool, to healthcare professionals who are not familiar with the wide range of services provided by the Hospice.

If you would like to request a copy of the DVD or would like further information, please contact Leanne Thorndyke, Marketing and Communications Assistant on 01473 707018 or email [leanne.thorndyke@stelizabethhospice.org.uk](mailto:leanne.thorndyke@stelizabethhospice.org.uk)