

SUFFOLK PALLIATIVE CARE

spotlight

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Welcome to Spotlight!

Welcome to the latest edition of Spotlight, the newsletter designed to keep you up-to-date with local palliative care matters, with particular focus in the West Suffolk area.

This newsletter will concentrate on the roles of those health and social care professionals who are looking after people with palliative care needs in their own home. One of the main points profiled in the End of Life Care Strategy (2009) was keeping those people who are dying in the specific place they would like. Although excellent end of life care may be given wherever the dying person is, there is now much more emphasis on preventing inappropriate hospital admissions when that person wants to die at home.

We hope you find this newsletter interesting and helpful. Please pass it on to anyone else who would also enjoy it.

Many thanks

Maddy Bass, Head of Education, St Nicholas Hospice Care

The care given in the person's home is coordinated, of high quality and follows the person's preferred choices.

HOW THE MULTI-DISCIPLINARY TEAM WORKS IN THE WEST

The Community Hospice Team (CHT) supports patients and their families in their own homes. But this valuable and crucial role can not be performed without partnerships with outside agencies.

In order to understand a patient's needs and preferences and to provide additional support, the team works with GPs, district nurses and social carers.

On the next page of this publication you will find a detailed graphic depicting how these partnerships work, giving a clear signal how important they are.

The Community Hospice Team is made up of:

- Clinical Nurse Specialists
- Nurses and Nursing Assistants
- A Consultant in Palliative Medicine
- Doctors
- Social Workers
- Complementary Therapists
- Chaplains
- A Physiotherapist
- An Occupational Therapist
- A Psychological Therapist
- Befrienders and Volunteers

All these people work together with a number of outside agencies to provide support and advice to patients and their families.

Through these partnerships, the Community Hospice Team strives to ensure patients and their families feel involved in decision-making and remain in control of their own care.



TAKING THE CRISIS OUT OF CRISES

The role of the GP in supporting patients who want to die at home.

**The word “crises” comes to mind!
So let us use it as an abbreviation:**

- C**ommunication – it is so important to keep everyone informed, be it the primary health care team, the out of hours service or the ambulance service. The latter can provide a form to advise the paramedics of any specific issues, for instance if the patient wants to die at home.
- R**eadiness – have sufficient drugs in the house for any syringe drivers and, as required, medication, whether it's analgesics, antiemetics or sedatives. Also have written instructions in the home and, if possible patient-held records as recommended by the Gold Standards Framework.
- I**nvolvement – the patient and their relatives must feel included in decision-making. The Hospice team may be a useful resource with the multi-disciplinary team involvement, be it nurses, doctors, physiotherapists, occupational therapists or family support.
- S**upport – the patient, relatives and care team.
- E**ducation – as GPs, we need to try and keep up-to-date through educational meetings and readings.
- S**ympathy – or empathy. Palliative care demands good communication skills.

Dr Jonathan Masters, GP and Hospice Physician.



Dr Jonathan Masters, GP and Hospice Physician

The patient and their relatives must feel included in decision-making

THE ROLE OF:

THE MARIE CURIE NURSE

My role is to provide end of life nursing care to people in their own homes. The Marie Curie Nursing Service is free at the point of care to all our patients. The service is available to people who have a life-threatening illness and choose to be at home.

I usually work at night although I am occasionally required to nurse people during the day. We work alone in our patients' homes but do work with other colleagues who are also caring for the patient such as the district nurse or Hospice nurses when we share information and ideas regarding care.

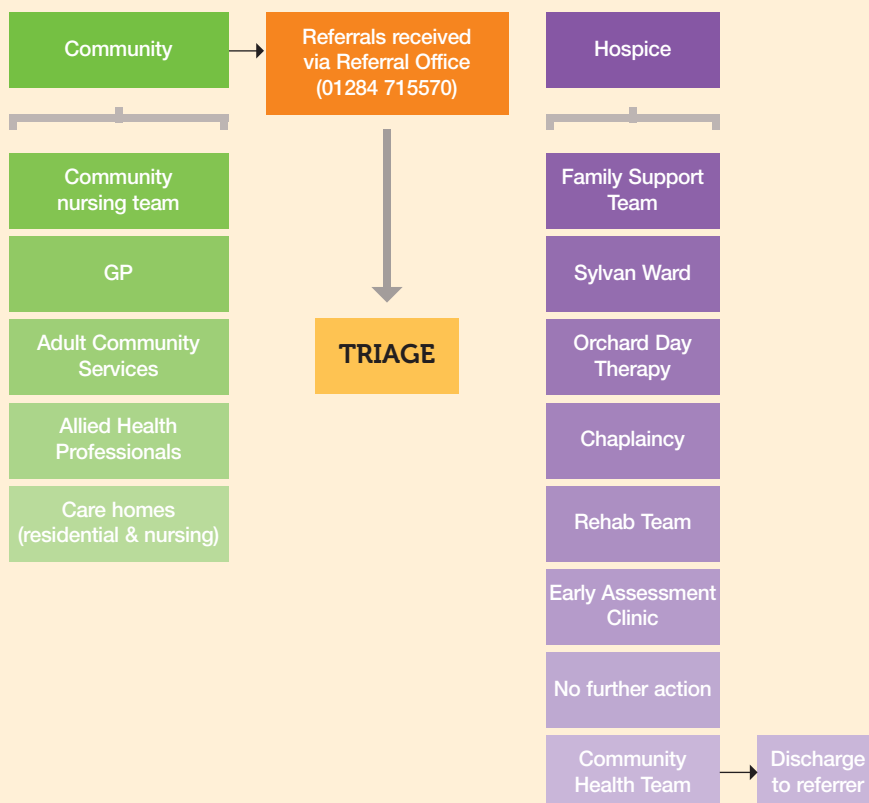
Marie Curie Cancer Care offers ongoing support and training which enables its nurses to give a professional service and work efficiently in the multi-disciplinary team.

Marie Curie Nurses very much enjoy the privileged role of end of life care, having the opportunity to be included in the team of professionals who enable people to be nursed at home and fulfil their wish to die in the place of their choice surrounded by loved ones.

Liz Foster, Registered Nurse working for Marie Curie Cancer Care.

ST NICHOLAS HOSPICE CARE COMMUNITY HOSPICE TEAM

Working within Hospice and community settings



Liz Foster, Marie Curie registered nurse

CARING PROFESSIONALS WORKING TOGETHER



Trish Muxlow knows first-hand about the support given to patients and families by the St Nicholas Hospice Care Community Hospice Team and other agencies.

When her beloved husband of 43 years, John, was diagnosed with a rare brain tumour earlier this year, caring professionals, working together, ensured his wish to die at home came true.

St Nicholas Hospice Care Community Nurse Specialists visited John at his village home ten times in the last four days of his life.

Trish said: "The Community Hospice Nurse Specialists were incredible. I know for a fact that I wouldn't have coped without them. Everyone in the team who came and so gently and professionally helped me look after John in those last few days were amazing. Once a terminal diagnosis had been reached, John wanted to die at home, and the Community Hospice Team, working with district nurses and other agencies, allowed this wish to be possible."

To thank St Nicholas Hospice Care, Trish is now embarking on a £10,000 fundraising drive - £1,000 for every time she was visited by the "wonderful" Community Hospice Team in John's last days.

Whilst dealing with her own grief, inspirational Trish has thrown all her energies into raising money for 'John's Fund'.

At the time of going to press, she had reached the halfway mark with more events planned later this year.

Trish said: "Fundraising is keeping me sane at the moment. I have been overwhelmed by the generosity of local people in the village and the kindness of businesses. John would have been so proud of how the community has supported me."

Everyone in the team who came and so gently and professionally helped me look after John in those last few days were amazing.

WHAT DO PEOPLE WHO ARE DYING REALLY NEED?

In a recent study-day* for health care support workers in adult community services, the group were asked what they felt to be important when people are dying, whether in a hospice, at home, in a hospital or in a care home.

Things they felt WERE needed:

- To have empathy, not sympathy.
- To be believed they are ill.
- To have fluids and nutrition offered to them without having to ask.
- To have the company of those they would like present.
- To have their everyday worries looked after by someone they trust.
- To have the right medication, if needed, to keep them comfortable at all times.
- To have control over decision and plans which include them and their future care.

Things they felt WERE NOT needed:

- Fuss.
- Too much noise.
- Decisions being made for them which they should be making themselves.
- Too many visitors.
- The 'wrong' people keeping them company.

*The End of Life Care for Health and Social Care Support Worker



HEALTHCARE ASSISTANTS IN THE COMMUNITY HOSPICE TEAM

Even before the creation of the Hospice at Home in March 2009, the driving force was the idea that helping people to stay in their own homes in the terminal phase of illness was something St Nicholas Hospice Care was proud to support.

There are currently four Healthcare Assistants who work alongside and are integrated with the Community Hospice Team – the Clinical Nurse Specialists.

The Healthcare Assistants work predominantly 'out of hours' including evenings, weekends and nights and are utilised in the following ways:

- Physical presence and 'hands-on' care in people's homes.
- Support for carers and families including listening skills.
- Telephone support, enabling them to feedback to the clinical nurse specialists. For example, family stress, symptom control issues.
- Liaising and sharing their experience with members of social services and primary care teams involved.
- Working collaboratively and pre-emptively to reduce inappropriate admissions to hospital where possible.

The Healthcare Assistant often becomes one of the key people from St Nicholas Hospice Care in dialogue with GPs, district nurses and carers from social services who help the patient achieve their wish to stay at home.

Sarah Flowers, Clinical Nurse Specialist

ST NICHOLAS HOSPICE CARE EDUCATION EVENTS

- **11 January:**
Is Reflection not Working, or am I not Working Reflectively?
- **27 January:**
Psycho-sexual Issues:
An introduction
- **12/15/19/22 February:**
Children and Grief:
Supporting the bereaved child
(4 day course).

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when you
need it most

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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 contributors' own and do not necessarily reflect those of the editorial board.

PALLIATIVE HEALTH CARE: JARGON BUSTER

Analgesic:

Medication which aims to relieve pain.

Anti-emetic:

Medication which aims to relieve nausea and vomiting.

Aperient:

Medication which aims to relieve constipation.

Ascites:

Fluid which has collected in the abdomen caused by advanced disease. It can often be drained off to make the patient more comfortable.

Dyspnoea:

Breathlessness.

End of Life Care Strategy (2008):

Published by the Department of Health, it outlines the aims and objectives for end of life care.

Gold Standards Framework (GSF):

A framework to deliver a 'gold standard' of care for all people approaching the end of their lives.

Life-limiting illness:

An incurable, terminal illness which affects length and/or functions of life.

Liverpool Care Pathway:

A care pathway which is to be used by all the multi-disciplinary care team, when the patient is in the last few days of life. It outlines the goals of care and what to do if they are not achieved.

Oncology:

The study of cancer.

Opiates:

Pain relieving medication of a specific group. It includes morphine, diamorphine, methadone, oxycodone.

Palliative Care:

Defined by the World Health Organisation as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative chemotherapy/radiotherapy:

Treatment which aims to prevent the growth or spread of cancer cells. It can be used to relieve certain symptoms, but it will not cure the patient.

Preferred Priorities for Care:

An approach which encourages patients/clients to state their choices in end of life care. The document is not legally binding but must be taken into account if the patient cannot speak for themselves.

Primary Care Team:

Community-based multi-disciplinary healthcare team, made up of GPs, district nurses and other professionals.

Sedatives:

Drugs which are used to reduce agitation and can help with sleep.

Syringe Driver:

A battery operated machine which delivers medication subcutaneously over many hours.

USEFUL WEBSITES:

Advanced Decision to Refuse: www.adrt.nhs.co.uk

East of England Strategic Health Authority: www.eoe.nhs.uk

End of Life Care – NHS: www.endoflifecareforadults.nhs.uk

Information on GSF in the community and care homes: www.goldstandardsframework.nhs.uk

Macmillan learning zone: learnzone.macmillan.org.uk

Marie Curie: www.mariecurie.org.uk

Palliative care policies and guidelines, research and audit information: www.palliativedrugs.com

St Nicholas Hospice Care: www.stnicholashospice.org.uk

Suffolk New College: www.suffolk.ac.uk

Syringe driver training, wound care training, on-line live lectures: www.cancernursing.org