Burdett Trust – Delivering Dignity through Empowered Leadership (2013/14)

Final Report
Hospital End of Life Care Champions Programme

Overview

Dorset has the highest proportion of population above retirement age of any county in the country (Dorset County Council 2010). Current trend predicts that by 2030 there will be a further 50% increase in people over retirement age and a 100% increase in those over 85 years of age (ONS 2008). The older population in Dorset is expected to continue to grow in number and stay ahead of the rest of the country, driven by an increase in life expectancy and a growing positive net migration in the pre-retirement (45 to 65 year old) age group. (Dorset County Council 2010)

Weldmar Hospicecare Trust is a registered charity which aims to ensure that all patients needing palliative care in Dorset have access to excellent services delivered where and when needed whether by Weldmar Hospicecare Trust or by others supported by the Trust.

Following a successful bid to the Burdett Trust a nurse led programme was devised that would encourage both acute and community hospital staff to take a lead in improving end of life care for their patients.

The Frances report (2012) gave scathing criticism as it evidenced a failure to provide dignified care to the frail and elderly. This programme aimed to focus on these elements and drive through improvements to the patient and carer's experience of End of Life Care in Dorset. The programme's aim was to encourage and support a culture where a human compassionate response is the natural one of choice and individuals are recognised and valued.

The programme had the full support of the hospice and is welcomed by both senior clinical leaders and management in the participating hospitals.

The programme had a steering group drawn from the key stakeholders of the Dorset County Hospital Foundation Trust, Dorset Healthcare University Foundation Trust and Weldmar Hospicecare Trust. The steering group guided the programme lead and ensured that reciprocal feedback occurred between itself and:

- The DCH Hospital End of Life Care Steering Group
- The Weldmar Hospicecare Trust Clinical Practice Group

- The Weldmar Hospicecare Trust Programme Group and Education Committee
- Director of Education at Weldmar Hospicecare Trust
- Community Associate Directors group across the community hospitals
- Audit Department at participating hospitals and hospice
- Through contract monitoring at the hospice the Clinical Commissioning Group were informed as the programme was reported on by the Education Department.

The Patient and Public experience lead (PPEL) within the Acute hospital was contacted and similarly the community hospital managers to ensure that the programme was well advertised and opportunity for feedback given through the PPEL and PALS office.

The Programme

In line with the submitted project plan, 3 study days were delivered to each staff group providing a varied timetable of clinical and developmental skills aimed at increasing the confidence of the Champions to speak up and advocate for their patients. Appendix 1 is an example of a day devised for registered staff

The participants, known as End of Life Care [EoLC] Champions, were empowered to advocate for the patient and improve services as a result. They were taught how to cascade their new knowledge and given support to embed new ways of working.

The programme brought together a total of 36 RGNs and Health Care Assistants working in acute and community hospitals in order to develop partnerships and promote collaborative working in the county.

The programme recognised that there are many levels of leadership within the healthcare system. It aimed to support the EoLC Champions to become EoLC transformational leaders in their clinical setting. This approach enabled participants to achieve results by influencing, motivating, and inspiring colleagues through their own practice.

The Programme ran from: September 2013 to September 2014. The initial workshop for each staff group was held in January with further workshops in March and July.

For the purposes of this programme we linked with the acute hospital audit and quality departments in order to evaluate the patient and carer outcomes of this programme. The programme utilised pre-existing patient / carer research. For this reason there were no consent or data protection issues as these had already been established.

Content

The content of the study days was bespoke, locally relevant and evidence based. The programme was tailored to meet the unique demographic need of the county and also to draw on best practice that is already in place. It gave opportunity to meet and discuss work being undertaken in the Care Homes in the county, many of which have Beacon status for End of Life Care through their implementation of the Gold Standards Framework. It is good for both acute and community hospitals to share learning and experience from these settings and for the EoLC Champions to understand the whole patient pathway.

The study days included such topics as:

- dignity in care
- allowing a natural death
- rapid discharge from hospital
- replacement of the Liverpool Care Pathway
- communicating with patients and families at end of life
- understanding bereavement and loss
- symptom control

The study days were delivered by experienced and qualified education facilitators employed by Weldmar Hospicecare Trust. The study days ran from well-equipped classrooms within our own buildings, with free parking, refreshments and all course materials provided all of which was much appreciated by the participants.

Carer Involvement

The programme invited the involvement of current patient and carers in participating in the classroom based programme with 2 carers giving first hand reports of the carer experience in a Question and Answer session. This provided unique feedback to staff on the Carer perspective and a chance for Carers to reflect on their contribution and impact on the type of support they received.

Learning in Practice

As part of the programme participants also undertook a 'Learning in Practice' day. This day was framed by the participants setting three personal objectives in advance and a retrospective sharing of their reflection and learning with their peers on the programme.

Providers of each placement were offered an honourarium of £25 as a thank you for their support.

Placements selected by participants included

- Local funeral directors
- Palliative care specialist nurse shadowing
- Soul Midwifery Induction day
- Acute Hospital Bereavement Services
- Acute oncology ward
- Hospital Mortuary
- Hospice inpatient unit
- Hospice community team

Dissemination

The programme was presented at the 10th Palliative Care Congress, Harrogate, 12-14 March 2014 and in addition, a Podcast was produced in partnership with the Wessex Health Innovation Education Cluster based at Southampton University which is now available on the stakeholder websites.

The hospice and hospital both have active Journal Club meetings where the outcomes will be presented and debated. Reports have been prepared for the Weldmar Hospicecare Trust Education Committee for ongoing reporting to the Board and also for the Director of Nursing at Dorset County Hospital and our Champions will keep information current and up to date on the End of Life Care noticeboards across their organisations.

Weldmar Hospicecare Trust hosts the Dorset Compassionate Communities which is a locality group of the national Dying Matters forum. This brings together regulated and non-regulated practitioners, patient /carers, conventional healthcare providers and complimentary therapists as well as funeral directors, solicitors, social care and third sector charities that offer End of Life Care support. This unique forum is an excellent arena in which to share the findings and receive constructive comment and public feedback.

Now completed, the programme will be jointly evaluated by the Lead Education Facilitator (programme nurse) and the Audit Department at Dorset County Hospital and the community hospital Associate Directors. Working with the Patient and Public Participations Lead for the Trust

patient and carer feedback to the Trust will be prospectively and retrospectively reviewed using key words of *elderly, dignity, care, communication*

Evaluation

Participants submitted an evaluation at the close of each study day. The overall evaluation has been extremely positive, capturing the Champions enthusiasm for the challenge of leading an improvement in End of Life Care and the positive application of their learning to practice.

Personal comments reflected every aspect of the original outcomes and are demonstrated below through the use of participants' own words when asked what they would take back into practice.

- To increased confidence for all participants in the EoLC Champions programme to speak up and advocate for their patients.
  "I feel far more confident in my role at work it is really good how [the facilitator] is giving us the confidence to talk to the people we work with."
- To improve communication skills amongst multi-disciplinary team within the hospital setting.
  "Make others more aware of what we can do as HCAs, being more involved with paperwork, expressing opinions"
- To increase collaboration between acute and community hospital staff
  "I will organise getting DNAR forms sent to OOH when discharging patients"
- To give skills and research based knowledge to underpin dignified care to the frail and elderly who are now in need of End of Life Care.
  "I have already delivered a short ward based teaching session detailing the signs and symptoms of dying to small groups of staff"
- To give insight and skill to participants so they can offer support to patients and their carers' at a time of transition, change and loss.
  "The patient and carer experience Q and A session helped me understand things from their perspective and understanding better how I can play a part in helping them to get the assistance they need."
- To enable patients and carers to access care delivered by staff who have knowledge and skills to enable informed choices for future care options.
  "*I am looking at how the Advance Care Planning booklet can be publicised on the ward for patients, relatives and staff. "*

Evidence in Practice.

During the course of the programme participants regularly shared areas of practice in which they had already started to implement change, challenge existing practice and lead the development of initiatives in their area of work. Examples given included

- The proposed implementation of a 'taste for pleasure' policy for patients at end of life who are normally NBM because of unsafe swallow.
- Challenging staff attitude to a terminally ill patient requesting a last cigarette.
- Facilitating a patient to eat their own food and educating staff that there is an existing policy to allow this.
- Cascading information and specific messages about End of Life patients
- 'Back of the Door' posters on Do Not Attempt Resuscitation policy
- Improving facilities in the relatives room through better lighting etc
- Sharing information with family, patients and relatives on the Advance Care Planning booklet.
- Dedicated areas for palliative care equipment
- Champion or Ward Sister to attend monthly District Nurse/Practice meetings to identify End of Life Care patients in the community who may need a hospital admission.
- Training volunteers/ League of Friends who can sit with patients and provide extra support when the ward is busy

Evidence of changes to practice

In addition to the list above 4 case studies have been documented. [Appendix 2] These case studies highlight actual changes to practice as a result of the programme. They include

- Dying with dignity rather than as 'hospital property'
- A patient with a brain tumour and the implementation of special dietary requests for patients identified as 'at end of life',
- The collaboration of 2 End of Life Champions from different departments in order to support a patients' wishes
- Improved practice in the delivery of medication.

Sustainability

Following discussion with the participants the momentum of the programme will be sustained through an Action Learning based End of Life Care Champions Forum that will be facilitated, in the first instance, by Weldmar Hospicecare Trust. This Forum will be an opportunity to share best practice and to further develop leadership initiatives in the practice of palliative care.

The ongoing evaluation process will use complaints, PALS feedback and reflections from patients and families to inform content of future study days and ideas for the Action Learning Sets and the programme lead will also liaise with the Bereavement Officer.

It will be the responsibility of individual champions to maintain the information folders and notice boards that they have developed in order to raise the profile of End of Life care and for individual participating organisations to continue their support for these champions in the workplace.

The Burdett Trust 'Delivering Dignity through Empowered Leadership' Grant has enabled this programme to be delivered and as a result we are confident that the care of elderly frail people at the end of their lives has been enhanced.

August 2014

Appendix 1

Appendix 2

Hospice Education Alliance
Releasing potential
Improving care

Burdett Trust for Nursing

Weldmar Hospicecare Trust
Caring for Dorset

Appendix 1

Hospital End of Life Care Champions Programme (Registered)

Day 3: 2nd July 2014
Facilitators:
Caroline Sweetland, Lead Education Facilitator, Hospice Education Alliance
Roz Simpson. HEA Associate

Time	Content	Facilitator
09.15	**Welcome and introductions** • Progress report since last study day	**All**
09.45	**Attributes of a skilled helper** • Exercise in pairs • PPP	RS
10.00	**Revisiting the EoLC Tools** review documents (ACP, LCP)	RS
10.30	**Routes to success publication** Small group exercise	RS
11.15	**Coffee**	
11.30	**Dignity in care** • Definitions Small group exercise	CS
12.15	**Care of the older person** Sculpt EoLC scenario	CS
12.45	**Lunch**	
13.30	**Rapid discharge from hospital** Review pathway and documentation	Anne Dixon
14.00	**Feedback from Learning in Practice day**	All
14.30	**The patient and carer experience** Q & A session	RS & Marilyn Fry
15.00	**Tea & cakes**	
15.15	**Self care** • Golf balls and mayonnaise jar	CS
15.30	**Summary** • Evaluations • Reflect with line manager at next 1:1 / appraisal • Ongoing roles and responsibilities • Forum dates	CS
16.00	**Close**	

Appendix 2

Case study 1

Dying with dignity rather than as 'hospital property'

After attending a session of the programme a Health Care Assistant noticed a dying patient lying on her back in a side room wearing a hospital gown with the words 'hospital property' printed all over it. The ward was very busy so the HCA offered to move the patient and change her nightgown etc. but was advised that there were other priorities and she was to leave the patient as she was.

As an End of Life Champion the HCA was upset at this response and was happy to find someone to help her and that her role as a 'Champion 'was not being respected and as an HCA was not being valued. She felt that dying in a hospital gown was not a dignified death and that the patient deserved better care so she took her concerns to the Matron. Following discussion it was agreed that the Champion could look at other ways of providing more suitable nightwear if the patient does not have any in addition to some personal care resources to be kept in a box in the event of someone dying. The Champion has also been invited to attend the Sister's meeting and to speak up with any ideas that she has about improving the care of the dying within the hospital.

Case study 2

A patient with a brain tumour and the implementation of special dietary requests for patients identified as 'at end of life',

Feeling empowered by the first Health Care Assistant study day one participant was caring for a lady on the ward who was dying. The patient had a brain tumour and was on steroids so had a very good appetite. One morning the HCA was helping her with her breakfast and the patient mentioned that she really missed scrambled eggs which she used to have for breakfast. The HCA went to speak to the chef in the hospital kitchen who said that she only had some frozen pre cooked scrambled egg. It was felt that this was not appropriate to this patient and asked about the possibility of fresh scrambled egg cooked for the patient. The chef did not believe this was possible but was persuaded that it would be a great thing to do to meet the wishes of a dying patient and would give them great satisfaction. The HCA also went to speak to the Matron and explained why she had taken that action in case there were any complaints about the change in protocol and financial implications. The Matron gave her full support to the idea and the patient was given scrambled egg the following morning which she absolutely loved. She continued to enjoy scrambled egg every morning until about 3 days before she died.

The HCA has continues to arrange alternative meals for patients at the End of Life in close negotiation with the catering team.

Case study 3

The collaboration of End of Life Champions to support a patients' wishes

In the course of her hospital stay a terminally ill patient was transferred from one ward to another. Following reassessment of her care the medical staff decided on a more aggressive approach which the End of Life Champion felt was at odds with the patient's and her family's wishes and understanding of the proposed plan of care. Meeting with the End of Life Champion in whose care the patient had been previously, a decision was made to respectfully challenge the medical team. Having just attended a session delivered by the newly appointed Palliative Care Nurse Specialist both Champions sought out this specialist and voiced their concern.

In consultation with the Palliative Care Nurse Specialist, the medical team, the patient and her family a decision was reached to step down the more aggressive medical interventions and allow a natural death as per the patient's original wishes.

Case study 4

Improved practice in the delivery of medication.

Attendance on the programme gave confidence to an experienced Health Care Assistant to discuss a patient's medication with the registered nurse in charge of the ward. A terminally ill patient in her care was experiencing repeated episodes of agitation and aggression for which she had been prescribed oral medication which was difficult to administer. Feeling empowered by the session on symptom control the HCA respectfully queried with the registered nurse if the medication could possibly be administered via a syringe driver. This course of action was investigated and the route of administration was changed. This resulted in a reduction in the patient's agitation through the delivery of a lower but consistent dose of medication and a more dignified level of care became possible.