HOSPICE OUTREACH TEAM

EVERY BREATH YOU TAKE : TRACHEOSTOMY

OFF-LABEL PRESCRIBING RECOMMENDATIONS BY A HOSPITAL PALLIATIVE CARE TEAM (HPCT)

Abstracts

• Fast track status reviewed early if not appropriate
• Coordination of care – having oversight of care at the end of life
• Having links to the hospice – work more effectively together
• Flexibility – challenge the standard ‘x2 carers/x4 a day request’ – refocus on patient-centred care

Typical 4-month stats (April - July 2019): Referrals – 296 and Care Hours - 6,331.75

Conclusion The primary objective of the service is to provide Individualised packages of care, increased/reduced according to need for patients in the last 6 weeks of life and those closest to them. Through this provision of home care, we are demonstrating that we can improve the assessment and management of symptoms.

Introduction The community nursing service was restructured to ensure that all adult people, regardless of their diagnosis, have choices and access to specialist palliative and end of life care; to strengthen the integration with our community colleagues; to improve anticipatory and advanced care planning; to reduce unplanned hospital admissions; and to ensure a timely response during episodes of palliative care crises.

Method To evidence a proposal for change an activity audit was completed, a triage system was tested, and views sought from GPs and community nursing leads. The team was changed and became comprised of two tiers of specialist nurse - Outreach Nurses and Outreach Practitioners who have extended skills of physical assessment and prescribing as well as overall responsibility for the wider caseload and the team. The service aimed to support GP’s and District Nursing teams within cluster locations. The telephone triage facility was used to determine the appropriateness of referrals and the location for the first assessment, allowing care to be prioritised and the team to offer a responsive service to complex and urgent cases.

Results By managing complex, individual and changing information and supporting patients in choices around treatment and care we have demonstrating improvement in quality and experience along with an increase in referrals. Using and applying clinical knowledge to oversee and coordinate services, we can personalise the palliative pathway for individual patients and support the needs of their families. Additionally, we can act as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce risk.

Typical 4-month stats (April – July 2019):
• Referrals - 695
• Home visits - 748
• Triage calls – 1307

Background It is well recognised that the off-label prescribing of medications is an essential part of practice in palliative care. ‘Off-label’ generally refers to a medicinal product that is used beyond the specification of its Marketing Authority. There are many reasons for the high incidence of such prescribing in palliative care including that the costly and time-intensive process of obtaining or expanding a licence can only be performed by a pharmaceutical company. Additionally, there is common use of subcutaneous medications, the majority of which are used off-label. While it is widely accepted as normal practice, there is a lack of standardisation regarding gaining informed consent from patients and its documentation.

Aim To gain information regarding the prevalence of off-label prescribing and address some of the issues that this presents.

Methods A retrospective study was conducted of the notes of patients referred to a HPCT over a 1 month period. All medications that were off-label (as determined by the Palliative Care Formulary, sixth edition and expert consensus) and recommended by the team were recorded including the drug, indication and route and whether by a HPCT consultant, doctor or Clinical Nurse Specialist (CNS).

Results 175 patients were referred. 541 drug recommendations were made, of which 266 (49%) were for off-label medications. The most commonly recommended off-label medications included opioids for breathlessness and levomepromazine for nausea and vomiting. All members of the HPCT made recommendations at a similar frequency.

Discussion By determining the prevalence of off-label prescribing, we have an understanding of the volume, patterns of drugs, doses and routes and doctor versus CNS variability. This will guide education of the HPCT, improve teaching throughout our Trust and inform the development of Patient Information documentation.

EVERY BREATH YOU TAKE : TRACHEOSTOMY VENTILATION IN CHILDREN’S PALLIATIVE CARE

Background Children’s palliative care is changing. Medical and technological advances enable an increasing number of children with life limiting conditions to survive on long term ventilation (LTV) via tracheostomy. A specialist hospital identified that children spend months in hospital awaiting adaptations to accommodation, and establishment of a care package.

Aims
• Set up a unit for tracheostomy ventilated children within a Children’s Hospice in partnership with the hospital. This unit would provide accommodation and nursing support for 3 children and families in preparation for discharge home.
• Facilitate care of child outside the hospital environment.

Methods October 2016-March 2017:
• Literature review
• Partnership working with respiratory team
• Agreed practice framework
March 2017–October 2017:
• Collaboration with specialist paediatric respiratory, and hospice palliative care teams
• Workforce planning
• Development of clinical pathways, policies and standard operating procedures; clinical governance
• Practice Education team develop LT1 Study day and Competency Framework, ongoing review of clinical knowledge and skills
• Preparation of children and families for transfer from High Dependency Unit to hospice.

Results

- November 2017: Admission of first tracheostomy and ventilated child and family from HDU to unit
- Child resident for 6 months, successful weaning off day time ventilation
- July 2018: Admission of second tracheostomy ventilated child from HDU to unit
- Child resident 4 months, discharged on weaning programme
- No complications or significant infections acquired by either child
- Saved hospital bed days: 308
- Staff competency increased from 47% to 93.5%
- Maintained good relationship with families.

Conclusion

With robust education and governance, tracheostomy ventilated children can be safely cared for in a hospice environment. Both sets of parents reported the environment had a positive impact on family dynamics and improved children’s physical health and emotional well-being.

A SURVEY TO EXPLORE THE EMOTIONAL WELL-BEING AND RESILIENCE OF A HOSPICE VOLUNTEER GROUP

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Purpose

Behind every great hospice is a great army of volunteers. Volunteers at the hospice front line are exposed to the grief, pain, distress and joy that comes from working in palliative care. This survey aimed to establish how supported our volunteers felt in facing that emotional challenge. Our pre-survey hypothesis was that volunteers may feel under-supported and distressed by the clinical situations they are exposed to and may require the hospice to introduce a more formalised system of supervision as is offered to trained members of staff.

Methods

A survey was designed collaboratively between a Palliative medicine consultant and Clinical Psychologist to be completed anonymously by volunteers within the inpatient unit and reception.

Results

In total 17 volunteers responded with a combined total of 135 years of volunteering experience between them. Over half of the responders had initially volunteered because of a personal contact with hospice care (57%). 100% stated meeting people (patients, visitors and staff) as their main source of enjoyment. Responders felt the most challenging times were when patients declined visitors so people had to be turned away (22%), when young patients are admitted (14%) or more practical issues i.e. phones not working (14%). Only one person had experienced a challenging scenario that had left them distressed. Universally this sample of volunteers felt they had someone to talk if they did find a situation challenging. A buddy system is used so they have a co-volunteer to share concerns with or would approach the staff nurse who has nominated responsibility to oversee the volunteers. The overall majority did not feel a more formal route of support was needed.

Implications

This survey, although limited by its small sample size, still proved our preconceptions wrong. Our volunteer body is resilient and the buddy system provides an internal support network that is well utilised.

ELECTRONIC HANDOVER DOCUMENT: ARE WE COMMUNICATING THE RIGHT INFORMATION IN THE RIGHT WAY?

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Background

At Compton Care specialist palliative inpatient unit, an electronic document is used to handover pertinent information to doctors providing out of hours cover,