Integrated and Palliative Care Pathway For Homeless and Vulnerably Housed Patients in Brighton and Hove

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Who Are We?
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- Our team: We are non-urgent community and hospital based integrated primary care team working for Sussex Community Foundation Trust. The team is made up of Nurses which includes an Advanced Nurse Practitioner, In-reach Hospital Nurse Specialist, Senior Nurse Band 6, Senior Nurse Band 5, 3 part-time Occupational Therapists, 1 part-time Physiotherapist and a part-time Health Care Assistant.

- Our speciality: We support homeless people engage with their physical health needs who have complex multiple care needs including: psychological health issues, substance misuse issues, social care needs, and palliative and long term chronic conditions.

- We support vulnerably housed patients throughout the city in hostels, emergency and temporary accommodation, rough sleeping, sofa surfing, and in day centres.

- Our mission: We aim to increase health and wellbeing inclusion for Brighton and Hove’s Homeless population.
The Martlets Hospice Palliative Care Team

- 18 bedded In Patient Unit: ‘2-4 week’ admissions for management of complex symptoms (palliation during the last year of life)
- Discharge Team: many return home following physio & OT home assessment with a package of care or nursing home
- Patient and Family support for those struggling to cope: social worker, counsellor (including bereavement service), Chaplain
- Improving quality of life: physio, complimentary therapies, ‘Sow & Grow’
- Volunteers
- Advance care planning including ReSPECT form: emergency care planning—rapidly accessible information for health care professionals needing to make immediate decisions about care and treatment in a crisis.
- End of life care (last weeks of life)
Community Palliative Care Team

- Clinical Nurse Specialist: case management (right care at the right time), assessment, symptom management, patient and family support
- Referral following GP or community nurse assessment via team email
- HUB community telephone support for patients, families, carers and health care professionals (Clinical Nurse Specialist daily. Staff nurses evenings & nights )

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- Community or Hospice out-patients Consultant assessment for complex symptom management
- Hospice at Home: nursing care at end of life.
- Day services: CNS assessment, complimentary therapies, physio, Martlets Choir, Sow & Grow, Chaplaincy, Social worker, Benefits advisor.
- Discharge Team are currently developing Volunteer Buddy Service to establish a rapport with those who are homeless/vulnerably housed to introduce and accompany such clients when accessing ANY of our services.
DEFINITION AND AIMS OF THE INTEGRATED PALLIATIVE CARE PATHWAY

• Definition: Clinical Pathways are Structured multidisciplinary plans of care

• Aims: To provide detailed guidance for each stage in the management of a patient’s palliative care needs

• To produce a series of algorithms in a flow chart format of the decisions to made and directions to take during the patients palliative care journey

• To provide guidance and education for frontline staff working with our patient group with links to services and further guidelines provided
Why create a Palliative Care Pathway

- In the past 18 months we had 12 patients who were palliative and died in our care either living in hostel or emergency accommodation with some cared for at the Martlets Hospice and some placed in nursing homes. Some have also chosen to be cared for at their hostels.
- Currently we have 14 patients with palliative care needs.
- Need for earlier identification of deteriorating/palliative patients
- Need to support and educate frontline staff. (Hostels work primarily with models of recovery)
- Need to identify other places of care for patients with substance misuse issues who are palliative.
- Need to breakdown barriers further for our patients to access the right level of support and care so they can be supported to die with dignity and respect.
- Need to improve on Advance Care Planning for our patients so they can express their wishes.
Case Study
Hostel pt

- Male, 44yrs
- 2016 recurrence of Chondrosarcoma of nasal septum (previous excision 2010) with pain and cranial nerve signs.
- Debulking surgery declined in 2018, no further treatment. Also Asthma
- History of childhood trauma/abuse and depression
- History of substance use denied by pt
- Frequent attendances for uncontrolled symptoms
Barriers to providing Palliative care

- Complex/variable behaviour which made communication difficult
- Prescribing for symptoms such as pain was difficult because patient was not clear how much he was using recreationally.
- Prognosis was unclear as patient refused/feared any further investigations or treatments
- Delays for patient in obtaining his methadone on the ward and diazepam to manage his substance misuse
- This led to patient frequently becoming angry and self discharging
- Hospice unable to accommodate the patient as he was behaviourally too complex. Limited choices also in context to nursing homes. Hostel had closed his room as they felt unable to meet his needs
- Limited social support or family contact.
- TOTAL PAIN (total distress) Impact on pain from psychological, social and spiritual distress
Overcoming Barriers

• Intensive engagement during admission work with pt, palliative care team and ward(s) around anxiety, fearful behaviours

• Package of care and support with medication management

• Progression of illness, increase in falls and admission relating to deterioration in health hostel (unable to support tenancy)

• D/c planning around CHC, placement to appropriate nursing/care environment

• Admitted and died peacefully at The Martlets Hospice
How to identify patients possibly in need of Palliative Support: Andrew Knee Palliative Care Coordinator St Mungo’s

Signs & Symptoms. Otherwise known as ‘Red Flags’

- Losing weight (unintentionally): Has lost a noticeable amount of weight over the past few months; or stays underweight.
- General physical decline – becoming more weak or frail
- Two or more unplanned hospital admissions in the past 6 months
- Withdrawal from social activities, becoming more isolated, or spending more time in their room
- Someone who is alcohol dependent not wanting a drink (for reason other than a change in their motivation) or not being able to drink much before they show signs of intoxication
- Tiring more easily, or becoming more breathless than usual
- Becoming more reliant on others to do the things they usually do (e.g. asking others to go to the shops for them)
- Swollen abdomen, particularly if this is new or worsening
- A change in their behaviour or personality
- Not eating or drinking
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.
The ‘Surprise Question’

“Would I be surprised if this person died in the next 6 to 12 months?”
Discuss Concerns

If you answered ‘no’ to the surprise question discuss your concerns with your manager or colleague. Speak with the individual and get their views on their own health. They will know within themselves if something is not right.

Medical Advice
With the client/patients consent speak to their GP or book an appointment to attend with them. Discuss your concerns and the red flags you’ve noticed. This will begin the first steps and provide guidance.

Referrals/Assessments
Once a diagnosis and prognosis have been confirmed then it is more easier to plan the care to support the individual and begin assessments.
- Clinical Specialist (i.e. Liver, Cancer, etc.)
- Continuing Health Care Assessment
- Adult Social Care
- Hospice

MDT Meetings
Once all referrals and assessments have been completed with the relevant professionals organise a multidisciplinary team (MDT) meeting to discuss:
- Area of concern/ care plans
- Timescales
- Support for staff in case of emergencies

The End of Life Care Pathway
Staff Support

Identify areas of support that the team will benefit from.
Hold team meetings to discuss the support available to staff whilst caring for an individual who is end of life care.
Listen to any concerns, risks, factors that may contribute to the environment being unsafe, and plan as a team.
Invite other professionals involved to speak.

My Wishes

There is never really a right time to have difficult conversations, but try and meet the individual and find out what their wishes are.
• What do they look to do?
• Do they have family? Or would they like to be informed?
• What do they enjoy doing?
• Always affirm life and the quality of life.

Preferred Place Of Death

Find out where the preferred place of death and work with the other agencies involved in the care to see whether this is feasible. This could be:
• Hostel
• Hospital
• Hospice

Persons Death

The saddest part of this journey is the passing of those we support. Everyone deserves to die with dignity and respect and to achieve a ‘Good Death.’
Funeral Arrangements
Depending on the individual's wishes, you can liaise with the local support services to assist with this.

- Family & Friends
- Hospital Patient Affairs/Bereavement Service
- Hospices
- Local Authority

Remembrance
Projects can hold their own remembrance services for those who have passed away for all who may have been unable to attend the funeral. Ideas can be:

- A list of names engraved on a plaque or wall
- Memorial bench
- Condolence book
- Planting a bush or tree in the garden
- Setting aside a part of the garden for reflection and remembrance
- Mosaic
- Holding a service for the deceased client
- A lasting memorial, so that people can see who it was for and names will not be forgotten

After Care/Bereavement Support
It is always sad when someone we cared for passes away. It is important to look after each other and also seek support from others. This can be in the form of:

- Team Debriefs with professionals
- Specialist bereavement support (group, 1:1)
- Team support and self-care
What Next?

• Establish palliative care **LINK PERSON(s)** in different settings across Brighton & Hove who support homeless & vulnerably housed people

• The Martlets Hospice **HOMELESSNESS SHAREPOINT**: access resources

• Advice and sign-posting is available 24/7 from the Hospice HUB community phone service for patients, family, carers and Health Care Professionals

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