Palliative Care in the Community

Aims

- To explore the practicalities of providing good palliative care in the community
- To understand the different services available to support you and your patients
- To know where to find the information you might need in the future
- To illustrate these using case examples
What services do you know that can be involved with your patient after a terminal diagnosis?

Different services

- Hospice services – outpatient clinic, day therapy, complementary therapy, inpatient services, hospice at home, occupational therapy and physiotherapy
- Hospital services – specialist consultant clinics, oncology, day units, specialist nurses, specialist physiotherapists
- Community services – Macmillan, district nurses, social workers and care agencies, nursing homes
- Others – support groups, Macmillan information service, Marie Curie
Case 1

George, 74, is diagnosed with lung cancer with brain metastases after an admission to hospital 'off legs'. He is discharged home to the house he shares with his wife and you are called out to see him at home as they’re struggling to manage.

- What do you want to know?
- How can you help him manage at home now?
- How might you help him and his wife prepare for the future?
- Are there any other agencies you might get involved at this point? What might they help with?

Case 1 – Key points

- Explore their ideas, concerns and expectations! Have they discussed prognosis?
- Think about support that’s available- they are likely to be eligible for financial support
  - DS1500
- Social work and Macmillan can support with applying for benefits and care
- Community OT and PT (Little Hulton or the hospice palliative team) can help set up home
- He may be a candidate for hospice day therapy (respite for wife)
- If they want to discuss future plans you could discuss their feelings about hospital admissions (admission avoidance care plan) or formal advance decisions to refuse treatment
  - DNACPR
DS1500

- Form that allows someone who is terminally ill to claim either Disability Living Allowance (<65) or Attendance Allowance (>65) at the higher rate under ‘special rules’
- Can be completed if the patient’s death can ‘reasonably be expected’ within 6 months

DNACPR

- Lilac NWAS forms – the lilac copy stays with the patient and their hospital/GP records keep a copy – at home keep in district nursing files
- Must be discussed with patient and/or carer
- Reason for decision must be A, B or C and properly completed
Case 2

- Michael is 78 with advanced COPD. His recent spirometry shows progression of his disease despite inhalers and nebulisers. He has had 4 courses of steroids and 3 hospital admissions in the last 6 months. His last discharge summary suggests you might want to consider him for the ‘Gold Standards Framework’
  - What do you want to discuss with Michael?
  - Who might be involved in his care?
  - What needs recording on his GP notes?

Case 2 key points

- The GSF is what we use to enable gold standard palliative care for patients with a prognosis of around 12 months or less. The aims are to provide quality care in line with their preferences, coordination and collaboration between providers, and supporting patients to live and die well in the place and manner of their choosing.
- This gentleman is entitled to much the same input as the first case-including Macmillan support. They are no longer just for cancer support. He may also have the respiratory nurses from the hospital in touch. Social work and hospice day therapy may again be helpful.
- Again you may want to consider discussions around understanding, prognosis, admission avoidance or DNACPR – and document those discussions, as well as coding him as ‘Palliative Care’, meaning his case will be discussed regularly.
Case 3

- Esmerelda is 90 and has advanced breast cancer for which she exhausted all treatment options 6 months ago. She is a retired nurse, strongly Catholic, and has always spoken openly about the fact she wants to die at home. She is starting to struggle with her oral medications, has spent much of the last 4 days in bed, and you believe her to be deteriorating with no reversible cause.
  - What do you need to know?
  - What do you need to discuss?
  - What paperwork do you need to complete if you aim to keep her at home for her end of life care?
  - Which other professionals can/should be involved?

Case 3 key points

- Her thoughts and wishes
- Who is important around her – does everyone that needs to know know how poorly she is? Who is your main contact?
- Spiritual needs- does she have someone in mind to contact?
- Paperwork
  - Statement of Intent
  - DNACPR
  - Community wardex
  - Adastra
- District nurses need to know, and consider hospice at home too.
- How much care can they have at home in the last days of life?
Statement of Intent

- Records that they are an expected death and that you will certify their death if they were to die in the next fortnight
- Why a fortnight?
- Why do we need this paperwork?
- Can you think of any reasons why you wouldn’t be able to put in a statement of intent? What might you need to discuss with the family?

Prescribing

- Anticipatory prescribing – consider keeping prescribing prompts in bags
- Ensure if on regular strong opiate medication has appropriate non-oral equivalent prescribed, as well as breakthrough doses
- Seek advice if advanced renal failure or any uncertainty
- If any concerns about what you should be prescribing who can you contact?
Case 4

You are working at out of hours and you get called to verify Joan, 84, who has just passed away in the local nursing home. She is not previously known to you. You are told that she had end-stage dementia and that it was an expected death.

- What do you want to know when you get there?
- What do you do after verification?

Case 4 key points

- Deaths at OOH- try and get as much information as possible to satisfy yourself with the story. Speak to family and staff. Check there were no concerns. Ask to see
  - Notes
  - DNACPR
  - Statement of Intent
- Don’t assume if a Statement of Intent is there that it definitely doesn’t need referral to coroner – in this case the patient was on a DOLS which is a reason for automatic referral
- You therefore have a duty to notify the police and explain to the family why you are doing so
- Log who was present at the time of death and their contact details – much easier for whoever does the eventual paperwork
Conclusions

- Palliative care in the community is a multidisciplinary affair
- Proper planning can reduce crisis situations and admissions
- Deaths at home take proper coordination, but can be achieved and be very rewarding
- Always consider reasons for referral to coroner before signing a statement of intent
- There is advice available 24hrs a day if needed from us here at the hospice – 01204 663066

References

- Macmillan Cancer Support www.macmillan.org.uk
- GP Notebook DS1500 www.gpnotebook.co.uk
- North West Ambulance Service Unified DNACPR Policy
- Gold Standards Framework www.goldstandardsframework.org.uk
- Bolton Palliative Care Guidelines