ENTERAL FEEDING ISSUES IN THE COMMUNITY

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Home Enteral Feed Specialist Dietitian
HEF DIETETIC SERVICE

• Service started in 2002 (HAZ funded – now substantive)
• 2 wte. Band 7 Dietitian
• 1 wte. Band 3 Assistant
CASELOAD

- Safe caseload........ 180 patients
- Actual caseload....... 285 patients
- Increasing by 10 – 15% each year
- 100+ new pts per year
- 50% CVA
- 30% H&N Cancer
- 20% Neuro
- £500k+ (estimated) saving on avoidable readmissions
CONSENT – WHAT FOR EXACTLY?

- PEG – Nutritional support (prolonged)
- HEF – potentially a lifelong commitment
HOME ENTERAL FEEDING
(POSSIBLY THE WORST DECISION WE EVER MADE)

• Will probably prolong life
• Ongoing care needs
• Complications
• Loss of capacity
• Withholding / withdrawing issues
• No significant improvement of clinical outcome
• The situation is improving*
PRE-PEG COUNSELLING SERVICE

• Provided by the HEF or Hospital Dietitian.
• Particularly relevant to chronic progressive conditions where the patient has capacity (MS, MND and HD).
• Close working with referrers such as NES and Palliative care services.
• Discuss – Advance Directives, LPA decisions and options for withholding / withdrawing feeding.
• Fully supported by the PEG CNS.
WHO TAKES THE LEAD?

- Need a clearly defined Team
- HEF Dietitian
- GP – at all key stages of life / death
- Palliative Care CNS
- Nursing staff
- Patients family
CALL THE DIETITIAN?

- Diarrhoea* – meds / feed / tolerance
- Constipation
- Nausea/vomiting* - meds / feed / tolerance
- Coughing/retching – volume/rate/positioning/tolerance
- Bloating
- Chest Infection v Aspiration Pneumonia – volume/rate/positioning/secrections*
- Secretions
- Training – CN’s, HCP’s, NS, carers, pts.
END OF LIFE

• What is End of Life?
• Who says so? (decisive)
• How long does it last?
• Does it go away? (a return to dying)
• Review?
• Is there a place for feeding at End of Life?
THE ETHICS OF FEEDING & HYDRATION
DIETETIC VIEW

- Feed in the absence of complications
- Alter feeds to counter complications
- Consider all medications
- Ensure adequate hydration
- Not our decision ‘to feed or not to feed’
CASE STUDY 1

86 year old lady, CVA June 2013, PEG placed 26th June 2013 and patient established on 5 Fortisip compact / day + pureed diet + thickened fluids. Patient discharged to a Nursing Home, remained stable for 6/12.

January 2014 patient refused all oral intake, her weight remained stable and she continued to tolerate the feeding regimen.

February – patient admitted to hospital with extension of CVA. Patient discharged back to nursing home on same feed regimen. Pt was minimally conscious and had deteriorated significantly.

20th February – patient was declared End of life by Palliative Care CNS, pts feed reduced to 2 Fortisip compact and 500mls water / day (as pt was chesty). The family were advised that the pt was dying and that pt comfort was now the sole priority.
The patient remained frail yet stable for 3 weeks. The GP advised the family that the pt was dying but was no longer End of life.

The PC CNS and HEF dietitian were so concerned that the pt was being starved that feeding was reintroduced (with GP approval) on 24th March. The pts family were very upset with this development and, when the pt developed diarrhoea 2 days later, a best interests meeting was convened. The GP did ask if they needed to be there.

27th March – best interests meeting, attended by GP, PC consultant, PC CNS, HEF dietitian, home NS and pts family. The family stated that the pt would not want this and should be allowed to die with dignity. However the outcome of the meeting was to restart the feed, albeit a more dilute feed, 500mls fed via a pump. (1 month feed ordered)

07th April – Pt still had diarrhoea, pt started on Loperamide prn, feed continued.

14th April – Pt chesty, oedematous and had diarrhoea. The GP, PC consultant and PC CNS decided pt was End of life, the feed was stopped, pt kept hydrated.
15th April – GP restarted the feed, with Loperamide prn, and advised that the feed should be reduced over a week until it is fully stopped. The PC consultant and CNS sought advice from the court of protection. The GP withdrew from all feed related discussions. The pt tolerated the feed so it was maintained at the reduced level.

23rd April – Best interests meeting – family very distressed as pts suffering being prolonged. Feeding to continue as at present with Loperamide prn (constantly). It was acknowledged that the feed was not meeting the pts requirements, that it could not be increased due to poor tolerance, but that it would continue as it was as pt was tolerating it.

24th May – pt died.

Q. Should the feed have been stopped as soon as it became clear that it would not be tolerated enough to meet the pts requirements?

Q. Hydration?
CASE STUDY 2

82 year old lady, CVA (with capacity), PEG placed in November 2013.
Oral diet in the day, pump feed overnight which she tolerated well.
Initial HEF consultation with pt and her family – pt made it clear that, should she deteriorate towards end of life, then she wanted the feed stopped.
The GP also discussed the matter with the pt and her family and documented the pts wishes in the notes.
19th September 2014 – pt had a further CVA, she became NBM therefore her feed was increased to meet her requirements, she tolerated this well.
14th October – pt had noticeably deteriorated, she developed diarrhoea, was chesty and bloated. The GP and PC CNS reviewed the pt and advised the nursing staff and pts family that the pt was now at End of life.
The pts feed was stopped, the pt continued on 500mls water plus medications
The pt died on 20th October, the pts family were relieved that she had not suffered.
WITHHOLDING / WITHDRAWING DILEMMA

• Are pts and their families aware of the EoL issues when consented for HEF? (is there any scope for PEG trials?)
• Should a tolerated feed / water be stopped at any point in a dying pt? (The sanctity of life)
• If stopped, should a dying pts feed be restarted?
• On who's authority (is a review planned)?
• Best interests meetings – GP led? (due to our disparate working)
• If tolerance is reliant upon medication, is there tolerance?
• Changing feeds / regimens – small local supplies.
• A secondary diagnosis – is a new review / decision possible?
SUMMARY

- Pre – Home Enteral Feeding consultations.
- Strong consultant / GP lead.
- Encourage MDT working.
- Facilitate Best Interests reviews at key stages.