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## Community Management of Palliative Long-term abdominal Drains in Refractory Ascites Due to Advanced Cirrhosis: Standard Operating Procedure

## After the long-term abdominal is inserted and prior to hospital discharge

- The hospital team will explain to the patient and informal caregivers how the long-term abdominal drain will be used and provide them with the drainage kit, which will include at least two weeks supply of drainage bags. The hospital team will provide patients with the long-term abdominal drain manufacturer information sheet and discharge letter, the latter also being sent to the GP and community nursing team. The discharge letter will state that patients have been discharged with a long-term abdominal drain. Long-term abdominal drain manufacturer details are included in the discharge letter. An additional community nurse referral will be sent to the community teams with basic instructions on long-term abdominal drain management.
- The hospital team will also contact the appropriate lead community nurse to update them. This will ensure that home visits can be organised by the community team to perform recurrent drainage and arrange necessary disposal of clinical waste. The hospital team will also inform the long-term abdominal drain manufacturer so that they can organise additional bespoke training and support for participants/informal caregivers if needed and ensure supply of drainage bags
- The patient and community teams will be provided with the contact number for the hospital team. The patients will also be provided with written information describing long-term abdominal drain management should the patient be admitted to hospital out of hours.

## **Community management**

- The community nurses will visit patients at their usual residence to carry out ascites drainage as clinically indicated but drainage episodes should be limited to a maximum of three times a week. If additional training is required, the community nursing teams should contact the long-term abdominal drain long-term abdominal drain as stated above. The amount to be drained will be dependent on clinical need, but would usually be 1-2L at a time with a maximum of 5L/week. Each time drainage is performed it will be recorded by the community nurses in a drainage diary which will be kept in the patient's usual place of residence.
- Additional drainage bags will be prescribed by the patients General Practitioner. The drainage bags will be disposed of in the usual way by the council as per standard arrangements in that region.
- The contact telephone number for the hospital team to be used "in hours" (9am-5pm) during week days will be provided to community teams. Out of hours, patients or community healthcare professionals should contact the out-of-hours GP service or the patients should attend Accident and Emergency (A&E) for emergency trial related problems.
- The community nurses will perform risk assessments during their home visits as per their usual practice and inform the hospital team of any concerns that have been identified as regards
  - Drain leakage or blockage
  - Cellulitis at the drain site
  - Abdominal pain not settling with usual analgesia i.e. suspicion of peritonitis

- Anything else which in the opinion of the community nurse is directly related to the long-term abdominal drain and requires hospitalisation
- Community nurses will train informal caregivers if they wish to perform drainage and also complete the drainage diary.
- If a participant dies, the long-term abdominal drain will be left in situ as per the usual practice. The community nursing team who will also follow standard procedures with regards to informing the undertakers of the presence of the long-term abdominal drain.
- It can be difficult for healthcare professionals involved in the care of any patient near the end of life, or actively dying and especially in a cohort with advanced liver disease, when death usually occurs in hospital. Hepatology teams should be available to debrief community staff if needed.

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