



St Mark's Intestinal Failure Patient Newsletter



January 2016

Snow and other adverse weather

Each of the homecare companies has an adverse weather plan. They will make every effort to deliver your feed as close to your scheduled delivery time as possible. During the winter months we would advise that you always have a supply of IV fluids which can be used in case the company is unable to deliver your feed. Also make sure you have enough spare ancillaries.

If you do get snowed in and the homecare company are unable to deliver;

- Contact your local council and explain you are on parenteral nutrition and need a delivery of essential medication.
- If your delivery is delayed for 48 hours then you will need to phone the emergency services and explain that you need to go to your local hospital for intravenous fluids.

For those of you who have nursing visits the companies also have a plan for this. You may be asked to switch the nights you feed or be connected for 24 hours if they are only able to make one visit per day.



Priority Service Register

Did you know that every gas and electricity supplier is obliged to have a Priority Service Register? People on this register will be offered extra help and priority treatment during a supply issue or power cut. Your water supplier may also have a similar register.

You will need to contact each supplier directly and ask about their register and how you apply to be on it. If you explain that you have a chronic condition and need to have constant access to electricity to run essential medical equipment, and hot water to be able to effectively wash your hands prior to accessing your line to prevent developing a serious infection this will most likely meet most companies criteria.



Invitation to participate in an intestinal failure PROM

Not, it is not a formal dance. We are working together with Galen Research to develop an intestinal failure PROM. A PROM is a Patient Reported Outcome Measure. To help create this assessment tool we have developed a questionnaire to determine your views. We believe that patients can provide the best insight into the impact of intestinal failure and its treatment (including parenteral nutrition) on day-to-day life. Once developed, the intestinal failure PROM will help us and other hospitals to improve services for patients with intestinal failure. Many thanks to all of you who have replied and sent back your questionnaires. If you have not yet sent it back please do as its not too late.

