

Levodopa-Carbidopa Intestinal Gel (LCIG) and Percutaneous Endoscopic Gastrostomy with Jejunal extension (PEG-J)

Information for patients



This leaflet is a general guide to LCIG and the PEG-J procedure. If you have any questions please contact the Parkinson's nurses on the number or email below.

Parkinson's disease (PD) is treated with oral tablets (by mouth) and non-oral therapies including patches, injections and infusions. LCIG is used in patients with advanced Parkinson's disease when other treatment options are not treating your symptoms effectively.

LCIG is a gel containing a combination of levodopa and carbidopa. It is delivered as a continuous infusion using a portable pump via a percutaneous jejunostomy (PEG-J) tube directly into the jejunum (small intestine).

The PEG-J insertion and the LCIG initiation are completed separately.

What is a PEG-J?

A PEG-J is a way of introducing medication directly into the small intestine. The PEG-J insertion is a surgical procedure and is usually performed under sedation and does not require a general anaesthetic (GA). A PEG-J tube is placed between the skin and stomach. It is inserted using a flexible tube with a camera on the end (Gastroscope). The camera is used to find the best position for the tubing in your small intestine. Once in position the PEG-J will be secured on the skin surface with a fixation device. The procedure usually takes about an hour.

The procedure for PEG-J insertion will be explained to you on the day, this leaflet explains the procedure, how you will need to prepare and what to expect on the day of the procedure. The doctors and nurses on the ward or in the endoscopy department will discuss any further questions you may have.

Some patients with pre-existing conditions may not be able to have a PEG-J and may need to be assessed for suitability for the Gastroenterology team.

Please let us know if you have any of the following medical conditions:

- Hiatus hernia
- Previous abdominal surgery
- Portal hypertension
- Ventriculoperitoneal (VP) shunt
- Severe respiratory (breathing) or cardiac (heart) problems.

What are the risks of having a PEG-J?

The risks associated with your PEG-J insertion will be discussed with you by the doctor when they go through the procedure with you. The main risks are detailed below.

It is important you are aware and understand the risks before agreeing to have the PEG-J tube inserted.

- Having a PEG-J carries a small risk of a perforation (a small hole) in your oesophagus (gullet), stomach or intestine from the Gastroscope. There is also a risk the bowel could be perforated. If this occurs and there is leakage of stomach or bowel contents, an operation may be necessary to repair it.
- Using sedation can affect your breathing. To reduce this risk your pulse and oxygen will be monitored.
- Although the PEG-J tube is inserted using a sterile (aseptic) technique, there is still a risk of infection around the tube site. Prior to your PEG-J insertion you will have specific preparation to minimise the possibility of an infection. If a temporary infection occurs, a course of antibiotics may be necessary.
- A chest infection (also known as pneumonia) can occur after like this when sedation is used for the PEG-J insertion.
- You may experience pain around where the tube has been inserted. If this is persistent the fixation device maybe too tight. This can be easily adjusted by the ward staff.
- Following the procedure you may experience a sore throat. This should ease after a few days.
- Rare complications include damage to loose teeth, crowns or dental bridgework.

These complications occur in approximately 20% of cases and are mostly related to infection around the site of the tube and leakage from around the tube.

A small percentage of patients develop a serious complication following their PEG-J insertion. For some patients these complications can be fatal. Patients with complicated medical history are more at risk. Your individual risks will be discussed with you by your doctor.

What preparation will I need?

Patients are admitted to one of neurology wards at the LGI the day before their PEG-J insertion. The ward staff will make sure you are prepared for your procedure. A PEG-J insertion must be performed on an empty stomach so the endoscopist can see the stomach and small intestine clearly; the ward will tell you when to stop eating and drinking.

A blood test will be taken before your PEG-J to check your blood is clotting normally.

You will have a small needle inserted into the back of your hand or in your arm. On the day of your PEG-J insertion the endoscopist will use this to give you some sedation. Sedation is not a general anaesthetic and will not put you to sleep, however it may make you feel relaxed and possibly a little drowsy.

You will be asked to sign a consent form; you will need to be aware of the risks (see above) before you complete your consent form.

Before your admission a pre-procedure assessment needs to be completed. This can be done over the telephone but you will need an ECG, swabs and blood tests done at the hospital.

You will have swabs taken from your nose, axilla (underarm) and groin to check for the bug called Methicillin-resistant Staphylococcus aureus or 'MRSA'. You will be required to use a five day course of ointment in your nose and liquid medicated soap hair and body wash.

We will arrange for the swabs and supply of hair and body wash to use five days before to finish on the day of your PEG-J insertion. ***If you do not complete this treatment your PEG-J will be cancelled.***

Do I keep taking my tablets?

You must continue taking any essential tablets including your Parkinson's medications, ***as prescribed with a sip of water only. If you are diabetic or taking any blood thinning tablets you will be advised by the medical staff.***

What will happen on the day of my procedure?

Before you leave the ward the nurse taking care of you will ensure that all your preparation has been completed. You will be asked to change into a hospital gown.

When you arrive at the endoscopy unit your personal details will be checked. The assessment nurse will check your medical history and any allergies.

You will be able to ask any questions and discuss any you may have about the procedure.

What happens in the procedure room?

You will be greeted by two nurses who will remain with you during the procedure. The nurses and the endoscopist will complete a checklist to ensure that all your information is correct. The two endoscopists carrying out the procedure will also be in the procedure room. You will be asked to remove any dentures or glasses and to lie down on the trolley on your back. During the procedure your pulse rate and oxygen level in your blood will be monitored by a probe placed on your finger.

Before the procedure starts a plastic mouthpiece is placed between your teeth to keep your mouth slightly open.

The doctor may spray your mouth with an antiseptic solution called Chlorhexidine. This reduces the risk of infection as the PEG-J tube is passed through your mouth. To reduce infection an antiseptic solution will also be used to clean the skin on your abdomen. ***Please tell the nurse or doctor if you are allergic or had skin reactions to antiseptic solutions in the past.***

After you have been given your sedation the endoscopist will gently pass the endoscope to the back of your tongue and into your stomach and into your jejunum (small intestine). It is normal to gag slightly but it will not interfere with your breathing.

Saliva and other secretions in your mouth and throat are removed using a suction tube similar to that used at the dentist.

An antiseptic solution will be used to clean the skin on your abdomen. A local anaesthetic will be used to numb the area where the PEG-J tube is to be placed. This may sting initially. Although you will feel some pressure and some prodding over your stomach, you should not feel any pain.

When the endoscopist has decided the best position for your PEG-J tube with the camera a small cut will be made in your skin for the PEG-J tube to pass through. The camera is removed at this point and replaced by the PEG-J tube. The position of the PEG-J tube is re-checked so you may be aware of the camera being passed through your mouth on two occasions.

Once in place a small plastic disc (bumper) inside the stomach stops the tube from falling out. A plastic fixator will be attached to the PEG-J tube on the outside of your abdomen and holds the PEG-J in position. Sometimes a small dressing is placed over the tube, but this is not always needed. The dressing will be removed in 24 hours.

If you become very uncomfortable the procedure will be stopped.

Please note: All the hospitals in the LTHT are teaching hospitals, trainee endoscopists may perform your procedure under the direct supervision of a consultant or fully trained registrar.

What happens after the procedure?

You will be transferred to the recovery room. It is likely your throat will feel sore and your stomach may feel sore and bloated, this should settle after a few days. The doctors on the ward will be able to prescribe some medication to help with the discomfort.

It is important to tell the nursing staff if you have any pain. You will have your pulse and blood pressure monitored to ensure there have been no complications. You will then return to the ward.

The endoscopy unit will give the ward a PEG-J integrated care pathway. This document tells you and the ward nurses how to look after your PEG-J immediately after it has been inserted and when you return home.

Oral feeding is possible two hours after PEG-J placement. Do not change the wound dressing during the first 24 hours unless necessary. Observe for signs of complications such as pain and bleeding.

The following days:

Over the next few hours and days your Peg-J tube will be flushed with water. The area around your PEG-J will need to be kept clean and dry.

The ward staff will instruct you or your carers how to manage your Peg-J tube, this will include:

- Daily flushing of the Jejunal tube (Green connector/end).
- Weekly flushing of the gastric tube (Blue connector/end).
- Advancing the tube to avoid a buried bumper (small plastic disc) ***never rotate the tube.***
- Observe for any pain or bleeding.

Daily procedure, day 1-10

The nursing staff will inspect, clean and dress your wound and check the tubing.

The nurses will show you how to open the retention plate and release the tubing from the plate and gently push and pull the tube into 3-4cm into the stomach until you feel the resistance of the internal bumper. This is to avoid a buried bumper, it is very important ***you do not twist the tube as it can dislodge the internal tube in your small intestine.***

Continuous care, every 2-3 days

Remove any dressings (if still applied), release the external plastic retention plate to allow free movement of the PEG/J tube.

Carefully push the tube 3-4 cm into the stomach and gently pull back until you feel resistance of the internal retention plate. ***Do not twist the tube.***

Replace the retention plate allowing free movement of 5-10 mm. Apply a Y-dressing-if needed.

Please note:

Always make sure the PEG-J area is clean and dry.

Do not go into the shower or bath wearing your pump.

Potential complications

Erythema (redness) less than 5 mm in diameter is normal and not necessarily a sign of wound infection- observe daily.

Never apply ointment on a PEG stoma or an inflamed PEG wound.

Encrusted dressing – remove with 0.9% saline solution.

Signs of inflammation – change the dressing twice a day and take a swab if necessary.

Severe discharge – keep the wound as dry as possible, change the dressing several times daily as necessary. It may need antibiotics to clear the infection.

Written information will be given how to look after your PEG-J tube.

If you are prone to constipation please take the medication you are usually prescribed or speak to the ward nurses or doctors for advice.

The nurses, doctors and dieticians can discuss any special dietary advice after the PEG-J insertion.

How long does the PEG-J tube stay in for?

The tubing is not routinely changed but can be changed in between if you have any problems with the tubing.

Starting the LCIG infusion

For LCIG initiation you will be admitted to the neurology ward for five to seven days and closely monitored by the neurology doctors, specialist nurses and ward nurses and doctors. Your usual medications for Parkinson's disease will be adjusted during the introduction of LCIG and your Parkinson's symptoms assessed until they are well controlled. The pump usually runs for 16 hours during the day and you will take tablets orally overnight.

The specialist LCIG nurses will show you the daily routine how to set up your pump and how to look after the PEG-J tubing. Written information and easy set up and troubleshooting guides are provided.

After your discharge from hospital

You will be discharged with a small supply of LCIG cassettes and syringes, the cassettes need to be stored in the fridge.

You will be supplied with an emergency prescription of oral medication in the event of a problem with the pump or tubing. Your GP will continue to ensure you have an up to date supply of tablets. Please let your GP know if you need a new supply of tablets.

The repeat prescriptions for the LCIG are written by Leeds Teaching Hospitals NHS Trust (LTHT) and delivered to your home. All your usual medications are prescribed as normal by your GP.

Specialist LCIG nurses will review you at home one week; one month; three months and six months after your discharge from hospital, then routinely in the hospital clinic by the Parkinson's specialist nurse and Consultant.

If you have worsening pain, a high temperature, vomiting leakage of pus or blood from the Peg-J site or it becomes red, swollen or hard to touch please telephone the hospital ward you were admitted to, your GP or NHS 111.

Useful contact details

Parkinson's disease and Movement disorders Specialist nurses

Phone: **0113 392 6689**

Email: pd.nurse@nhs.net

Neurology Ward L17
Leeds General Infirmary
F Floor Jubilee Wing
0113 3927417

Endoscopy department

Leeds General Infirmary **0113 392 8675**
B Floor Clarendon Wing

St James's University Hospital **0113 206 8279**
Bexley Wing

If you are admitted to hospital please ask the staff to contact the specialist nurses (in office hours Monday-Friday) or L17 neurology ward at the LGI (out of hours).

Leeds Teaching Hospitals (LTHT) staff can access Parkinson's information including infusion set up guides and troubleshooting can be found on the LTHT intranet.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



© The Leeds Teaching Hospitals NHS Trust • 1st edition (Ver 1)
Developed by: Philippa Duggan-Carter, Parkinson's and Movement Disorders
Specialist Nurse • Leeds Centre for Neurosciences
Produced by: Medical Illustration Services • MID code: 20221205_005/EP

LN005504
Publication date
03/2023
Review date
03/2026