



British Pain Society

Intrathecal drug delivery systems for
treating pain and spasms - Information for
patients

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Intrathecal drug delivery systems for treating pain and spasms - Information for patients

Your hospital specialist team thinks that you might benefit from having an intrathecal drug delivery (ITDD) system; a means of delivering medicine very close to the spine for increased effectiveness. This system is often just called a 'pump'.

This booklet tells you about ITDD systems. It gives you some of the information that you might need before you can decide whether this might be right for you.

Living with chronic pain or spasms

You have almost certainly been in pain or have been troubled with spasms for a long time.

If you have been in pain for a long time it might have changed the way you live your life and/or the way you feel about yourself. It is common to experience all sorts of complicated feelings such as frustration, anger, worry or a sense of helplessness and despair.

Why might a pump help me?

If you have persistent pain or muscle spasm you might be taking regular medication to relieve your symptoms. You might find that you do not get as much benefit from the medication or that the side effects become unbearable. Over time, some people find that they do not get as much benefit from the medication or that the side effects become unbearable.

A pump (see Figure 1) delivers medication directly to the (intrathecal) space in your spine. Your spine is made up of a number of bony supports at the front and arches at the back. At the centre of these arches lies the spinal cord. The spinal cord links your brain to the other nerves in your body. The cord floats in spinal fluid in a space called the intrathecal space. This fluid is made in the brain with the aim of cushioning the brain and spinal cord.

Because your pump delivers your medicine very close to your nerves you need lower doses.

A pump is not a cure and may not get rid of all of your pain or spasm. You may still have to take other medicines. However, it can be a better way to control your symptoms than your current drugs. This may mean you can become more active, return to more of your everyday activities and enjoy better sleep. There are three parts to an ITDD system:

- 1 **The actual pump**, a small battery-powered device that is implanted into your abdominal area.
- 2 A thin, flexible tube (**catheter**) that is connected to the pump and implanted into the fluid filled space in your spine (Figure 2) known as the intrathecal space.
- 3 **An external programmer**, which is used by your doctor or nurse to communicate with and programme your pump during your refill and check-up sessions.

The pump is filled with medicine that is released at a set rate, through the catheter, into your intrathecal space.



Figure 1. Two different models of pumps with the catheter tubing attached. (Images reproduced with permission from Medtronic UK and Flowonix (UK) LTD).

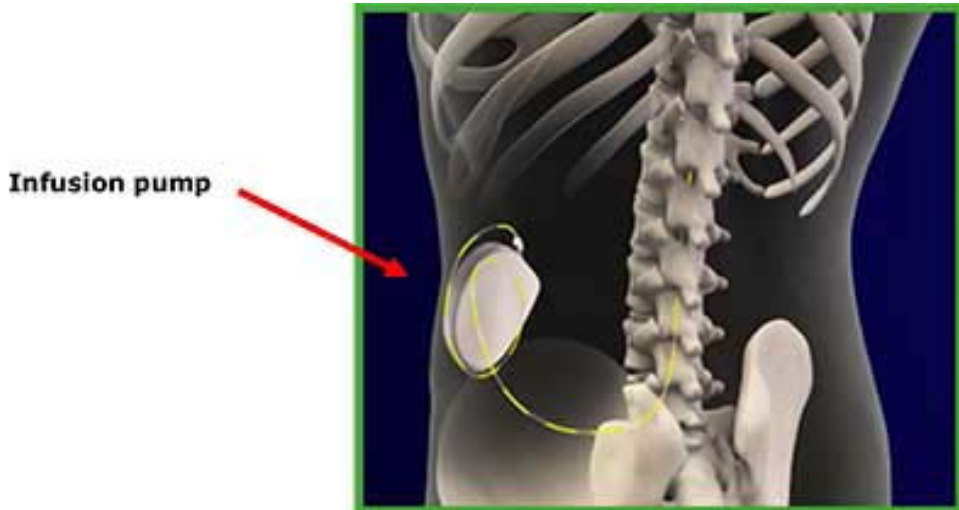


Figure 2. An implanted pump with tubing and catheter in position in the fluid filled spinal space

How effective is ITDD?

Your specialist will decide whether they think a pump may benefit you. Ask your specialist what its results are for people with your particular condition.

Even if you get good pain relief from your pump, it will only be one part of the overall plan to manage your pain.

Will I need to travel to a specialist centre for ITDD?

Generally, ITDD is only available at specialist centres, which have a lot of experience using this technique and have enough staff to offer patients care whenever they need it.

This may mean that you have to be prepared to travel some distance to a suitable centre. You need to consider whether you are willing and able to travel when you are in pain. You will also need to decide whether you will be able to afford the travel costs of the journey. You might be eligible to claim a refund of reasonable travel costs under the Healthcare Travel Costs Scheme. For further information visit: <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx>. Remember that you will have to make regular visits for pump refills. How often your pump needs refilling will be discussed with you.

Will my usual doctor know how to adjust my medication?

Only the specialist team will adjust your medication and let your GP know about the change. Your GP can contact a member of the team if they need to find out more about the medication you have been given.

How does the screening process work?

ITDD does not work for everyone or every condition. If your specialist thinks it might help you, a screening process, also known as a 'trial', will be carried out before you and your doctors consider giving you a permanent pump. This allows you and your specialist team to decide how well the system will work to reduce your pain or muscle spasm.

Before the trial, there will be a thorough assessment of your pain and its effect on you and your day-to-day life.

What happens during the trial?

For the trial, you will have to be admitted to hospital. While you are there, the medical team will insert a tube into your intrathecal space under local anaesthetic. The tube comes out through the skin. The team will give various medicines to you through the tube at different times, and decide how useful these are to you. You will not normally know which medicines you are having. When the trial is finished, the tube will be removed. If your trial is successful and you get good pain relief, you and your doctors may decide that you should go on to have a permanent implant.

How is the permanent pump inserted?

If you have the permanent pump, you will have to return to hospital. The operation is done under general or spinal (numbing from the waist down) anaesthetic. The surgery involves implanting the pump into a small pocket under the skin of your abdomen. The pump is then connected to the catheter that is inserted into the fluid filled intrathecal space that surrounds your spine.

After surgery you may experience some discomfort around the area where you have the implant, which can be treated with simple painkillers. This usually settles over the next few days and it is important to become more active because this will help you to recover more quickly.

The pump is filled with medicine and programmed while you are still in hospital. This is done by the specialist staff at the hospital using the external programmer that can communicate with your pump to make these changes.

Implanting the pump will require staying in hospital for a few days. However, as soon as the most suitable medicine for you have been found, you will be allowed home. You may have clips to close the wound and these will be taken out after seven days. You should gradually increase your activity over this time, and you will be reviewed by the team. At the time of the review your pump will be refilled.

It is very important that you get 24-hour contact numbers before you leave hospital in case you have any problems with the implant.

During the first few days or weeks after surgery, the dose of medicine in the pump may need to be adjusted to give you the best results.

To get the best possible pain relief, it is vital that you make regular visits to the centre where you had the implant for follow-up care.

This usually means that you will need to have a follow-up visit roughly every three to six months, depending on the type of pump you have, and how much medication you need. The refill date will be agreed during your follow-up appointments. When you have follow-up sessions, the pump is usually emptied and refilled by a sterile injection through the skin on your abdomen. This is a relatively easy and usually painless procedure. If necessary, the team can adjust your dosage in these sessions.

This visit will take about one hour and you can drive yourself home if you want.

You will need to get the pump refilled before it runs out, to manage your pain or spasms effectively. Therefore, it is very important that you keep to your appointments.

How long does the pump last?

The pump is powered by a small internal battery. This can last between three and ten years, depending on the type of pump. If the battery needs to be changed, you will need to stay in hospital overnight and you will usually need an anaesthetic, either a spinal or general.

What are the risks and possible complications of a pump?

As with any procedure, there are some possible risks and complications.

It is common for patients who undergo the trial to experience mild back pain where the catheter is inserted. This is not a serious complication and usually only lasts a few days. Some people also report headaches, again lasting a few days.

During the trial and after the pump is installed, there can be side effects from the medicine that is being infused such as nausea and vomiting, itching and problems passing urine. All of these problems are temporary and can be easily treated.

Some side-effects of the drug can be potentially serious, such as breathing problems and sedation. During the trial and in the first few days after the pump has been inserted, the team will monitor you closely so that they can treat any side-effects quickly.

Complications such as spinal fluid leaks, infection, meningitis, abscesses, bruising and damage to the spinal cord, scar tissue formation, catheter problems or pump malfunction can happen but they are very rare.

In very rare incidents a pump can be refilled with the wrong medication or be programmed to deliver the wrong dose. However, great care is taken by your treatment team to avoid this. If you feel unwell after your refill contact your treatment centre urgently.

How will I know when a refill is due?

At the time of each refill you will be given an appointment that falls one to two weeks before the date your pump is due to alarm. If your pump needs to be refilled before this scheduled appointment, you may hear the pump alarm or find your pain or spasm is not being as well controlled.

How often does my pump have to be refilled?

This will depend on the type of pump you have and how quickly the drug is released. However, this is likely to be about every three to six months.

How long does the refill take?

This can vary but usually takes about 30 to 45 minutes.

What happens if my pump runs out of medicine?

What happens if the pump stops can vary depending on the type of medicine you have been receiving. The effect, if you stop taking morphine or baclofen can be very serious. You should ask your doctor what the effects would be if the pump ran out of medicine, and what you should do if this happens. It is important that you keep to your refill appointments to stop the pump running out of medication. The pump can be seriously damaged if the medication runs out. An alarm will sound when the pump is using its reserve volume.

What do I need to do when I go home?

Keep your wounds dry and clean until they have healed and the stitches or staples have been removed. Check your wounds daily and look out for any signs of infection such as redness, swelling or discharge. You do not need to remove the dressing to check your wound. If you suspect you have an infection, you feel unwell or your wounds are red, hot or tender; contact your treatment centre as soon as possible. Make sure you have the contact details to hand.

How long will it take me to recover?

You will be able to carry out:

- occasional light lifting, three weeks after surgery;
- work and driving, four to six weeks after surgery; and
- lifting heavier items, twelve weeks after surgery.

These timescales are only a guide and may vary for different people.

How soon will I start to feel benefit from the ITDD?

You may not notice the benefit of having the ITDD system for several weeks. Your doctor may gradually reduce your pain or spasm medicine over this time.

If I may not notice the benefit for several weeks, what use is the trial?

During the trial, doctors will use higher doses of medicines than you would normally need. This means your body responds more quickly, meaning the doctor will be able to find out sooner whether it will help you.

What if my pain relief does not improve after the ITDD is implanted?

You should let your doctor know. They may change the dose or type of medicine used in the pump.

What types of medication can my pump be filled with?

The pump is usually filled with a strong pain killer such as morphine or an anti-spasm medicine such as baclofen. In some cases combinations of medicines may be used by your doctor. Ask your doctor about the type of medicine and if a combination is used.

Can I stop taking other medicines if I have the pump?

You may be able to, but you should follow the advice of your doctor.

Can I take hot baths, showers or go on sun beds?

You should take care in very hot baths or on sun beds. Discuss this with your doctor or nurse.

Will people be able to see that I have a pump?

People may be able to see the small swelling over the area where the pump is implanted.

Will it affect what clothes I can wear in terms of comfort or possible discomfort? If so, how?

The pump is placed where it is least likely to get in the way of belts and waistbands. Tight clothing may make the pump visible. Someone will discuss this with you before the procedure.

Will I be uncomfortable or at risk wearing a seat belt?

When the specialist team decide where to place the pump, they will consider your comfort. So far no risk of using a seatbelt has been identified.

Can I fly and scuba dive?

Pump manufacturers state you are safe as long as you do not go higher than 7000 feet above sea level, or more than 70 feet under water. Most standard and long haul flights will not affect your pump. Your nurse or physiotherapist can discuss any effects with you.

When can I return to sport?

You can start walking again when you feel well enough and start swimming when your wounds have healed. You should gradually build back up to other sports over the following six to eight weeks. If you feel the pump moving it is advisable to wear something closefitting to limit this. Your physiotherapist or nurse will give you more information about this. You should avoid contact sports such as rugby as they could cause the catheter to move out of the correct position. If your catheter becomes dislodged after a fall or a blow, you will probably find that your pain is controlled less effectively, you might notice swelling or fluid where the pump was installed in your body, and start to feel generally unwell. If this happens you should contact the team as soon as possible, or the ward if it happens out of working hours.

Technical questions about ITDD

What happens when my battery runs out?

When the pump battery needs to be replaced you will need to stay in hospital for a short period. This will generally involve an anaesthetic.

Is there an alarm to show there is a problem with the pump?

There are alarms which warn you that the medicine level is low, that the battery is low or that there is a problem with the pump. These alarms vary from device to device. Your doctor and nurse will discuss with you what the alarms sound like and what they mean before you leave hospital with the pump in.

If I hear the alarm, how long do I have before the battery runs out?

Your pump should be refilled before the alarm goes off. If you hear the low-battery alarm, you should arrange to have your battery replaced immediately.

Will electrical equipment interfere with the pump?

Most electrical equipment such as mobile phones, microwaves and household tools will not interfere with the pump. However some large industrial equipment may have an effect. Because of this, you should avoid getting too close to industrial welding equipment, or equipment that creates a strong electromagnetic field.

Certain treatments can also interfere with your pump, such as short-wave diathermy (heating deep tissue using electricity), radiotherapy, therapeutic ultrasound and bone-growth stimulators. It is therefore important that you let your dentist and physiotherapist know that you have a pump.

Standard x-rays will not interfere with the pump but MRI scans may interfere with the function of some pump models and a check after the scan is advised. Other pump models may need to be emptied before the scan and refilled following the completion of the scan. If you need an MRI scan, tell the radiologist that you have a pump before you go to your appointment.

Will security devices interfere with my pump?

Anti theft or security devices will not affect how well your pump works. However, the metal in the pump may cause certain security devices to set off an alarm, for example those found in airports, shops and libraries. It is advisable to carry your ID card with you in case this happens. (This will be given to you by the hospital when you have the pump put in.)

Can the catheter become dislodged or tear?

The catheter can be dislodged or tear if you move suddenly or vigorously. You should take care if you exercise or move quickly. You can discuss this with your doctor or nurse.

If you have any further questions or concerns you should discuss these with your doctor or nurse.

The working party

The following people contributed to the original version

Doctor Kate Grady (Chairperson & Editor) and Professor Jon Raphael (Editor), Ms Sue Clayton, Mr Paul R Eldridge, Doctor Peter Hargreaves, Doctor Francis Luscombe, Professor Stephen Morley, Ms Jane Southall, Mrs Heather Wallace, Doctor John Williams

The following people contributed to the revised version

Professor Sam Eldabe, Ms Felicia Cox

Competing interests

Members of the revision working party have declared their competing interests (financial connections with companies that are involved in intrathecal drug delivery systems that might influence advice) as follows.

Professor Eldabe has declared:

- implants devices manufactured by Medtronic (a company which produces treatments for chronic pain)
- has been performing research on using ITDD in pain treatment
- has acted as consultant to Medtronic and received payment for this

Ms Felicia Cox has declared no competing interests.



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