Things You Might Want to Know About Your Driver or Pump

Niki T34 Syringe Driver

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Booklet originally developed by
The Centre for Palliative Care Research and Education
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What is a subcutaneous infusion device?

- It is a very reliable, battery powered, portable pump.
- Sometimes these devices are called a driver or a pump. The term ‘driver’ will generally be used in this document.
- They are used to deliver medications at a steady rate under the skin, usually over 24 hours.
- They are simple machines to help keep pain and other symptoms under control without the need for constant injections.
- There are many different types of these devices but they all do the same thing.

Why do I need one?

- You may be having difficulty swallowing your medicines.
- Or you may have been vomiting and not able to take your tablets.
- Giving medications under the skin means they are absorbed into your system to help control your symptoms.
- It’s just another way for you to have medications to keep you as comfortable as possible.

How does it work?

- An infusion simply means the medication is going into the body.
- A subcutaneous infusion means the medications are delivered just under the skin to be absorbed by the body.
- The infusion device very slowly pumps the medication through a small needle (known as a cannula) into the space just under the skin.
Important Contacts and Numbers

Palliative care team
Your doctor is ________________________________
Telephone: ________________________________
Your nurse is ________________________________
Telephone: ________________________________
Your social worker/counsellor is ________________________________
Telephone: ________________________________
After hours number: ________________________________

GP (General Practitioner) ________________________________
Telephone: ________________________________
After hours number: ________________________________

Pharmacist (Chemist) ________________________________
Telephone: ________________________________

Public Trustee ________________________________

Local Carer Organisation ________________________________

Will I need to do anything special to look after it?

- The visiting nurse will prepare the medications that you will receive via the driver.
- If you are being cared for at home, the nurse will show you what to look for on the driver to know that it is working.
- The driver may make a ‘whirring’ noise, have a small flashing light or on-screen message to indicate it is working normally.
- It is a good idea to check those signs (whirring noise, flashing light or message) occasionally during the day.
- The driver is battery powered and will need to have its batteries changed every couple of days.
- Your nurse will show you how to do this in case batteries need changing when the nurse is not there. It is a good idea to practise changing the batteries when your nurse is present so you are confident about it.
- It is important to have a spare battery available.
- The batteries needed for your driver are: __________ (number and type e.g. 2x AA)

What will I do if something happens to it?

If you think something has happened to the driver or if you are worried it is not working properly:

- Contact your nurse, GP (general practitioner) or palliative care team – see the contact information on the back page.
- The driver will alarm if it runs out of medications, or if there is a blockage in the tubing going from the driver to you.
- Your palliative care nurse will explain what the alarm sounds like for the driver you are using. If the alarm does sound don’t panic. The reasons are often simple to fix and will be able to be sorted by your nurse or palliative care team.
Will I be able to do my normal activities?

These devices are designed to make your life more comfortable and help you continue with your preferred daily activities. Your nurse will discuss with you ways to incorporate the device into your everyday life.

• You may notice you do not feel as alert as usual after starting the subcutaneous medications and you may feel quite sleepy. This is a normal effect of the medications and usually settles within a day or so. You should discuss those changes with your nurse, GP or palliative care team and if it continues for longer and is a problem for you, they will discuss with you adjusting the medications.

• Because drowsiness caused by the medications may affect your reflexes and responses, it is important you discuss continuing to drive your car or vehicle with your GP or palliative care team. They will advise you about the safety of you continuing to drive.

• When you have your bath or shower, the driver can be disconnected but this should be for as short a time as possible. Your nurse will show you how to safely disconnect and reconnect the driver, and what to do if you have a problem.

• You may need to take more notice of the clothes you wear. Fitted sleeves or trousers may not be the best choice if they make it difficult for your nurse to access the site.

• You can continue to eat and drink your normal diet after the driver starts. You may notice if you drink alcohol that its effects are increased by the medications you are receiving. It is suggested you keep alcohol intake to a minimum.

Some troubleshooting guidelines

<table>
<thead>
<tr>
<th>Situation</th>
<th>Recommendation</th>
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<tbody>
<tr>
<td>If you think the device is not working properly</td>
<td>Check that the light is flashing, if a Niki or Graseby.</td>
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<tr>
<td>The green light is not flashing (Niki or Graseby)</td>
<td>Change the battery if you have been taught how to do it, or have clear instructions and are confident to do it.</td>
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<tr>
<td>Syringe is disconnected</td>
<td>Contact your palliative care or other service (your team), You may need help to reconnect the syringe.</td>
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<tr>
<td>The tubing from the syringe or device to the patient is twisted or kinked</td>
<td>Try to gently and carefully untwist the tubing</td>
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<tr>
<td>Syringe is empty</td>
<td>Contact team</td>
</tr>
<tr>
<td>Cannula into the skin has come out</td>
<td>Contact team</td>
</tr>
<tr>
<td>Pain at the site of the cannula</td>
<td>Contact team</td>
</tr>
<tr>
<td>Blood at the site of the cannula</td>
<td>Contact team</td>
</tr>
<tr>
<td>Extra pain</td>
<td>Follow instructions given for dealing with pain. If no instructions or following them does not work, contact the team.</td>
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<tr>
<td>Showering</td>
<td>The device must not come into contact with water. Follow your team’s instructions about disconnecting before your shower and reconnecting afterwards.</td>
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References

Equipment disposal

Your nurse or palliative care team member will advise and help with safe disposal of equipment and unneeded medications when necessary.

Other information and links

Consumer medicine and symptom guide. Available from:

Palliative caring at home: a guide for carers who are caring for a terminally ill person at home. Available from

Note: Sometimes family/carers or patients find information on the internet (or from friends/other family members) that is different to what the palliative care team, GP or pharmacist might advise. Before acting on any such information, discuss it with your palliative care team, GP or pharmacist in case a change you make interferes with the treatment suggested by the palliative care team.

Who will look after the medications?

Your palliative care team, GP and pharmacist will help you to understand any new medications and possible effects of this new way to receive them.

- To ensure a constant supply of medications you should organise your next prescription 2-3 days before your medication supply runs out. Your palliative care team and GP will be able to help with monitoring this.
- Side effects might include nausea, dizziness, or a skin rash, however such symptoms could be related to something else and not your medication. It is important that you discuss your medications with your nurse, doctor or pharmacist to understand possible side effects and how they can be managed if they occur. If you think you may be experiencing side effects of your medications, or if you have other concerns, discuss this with your palliative care team or GP.
- All medications should be stored in a cool, dry, clean place. For everyone’s safety, they should be stored away from children, visitors and pets, in a locked cupboard if available. When medications are no longer needed, return them to your pharmacist for safe disposal.

What if my pain/other symptom gets worse?

If your pain or other symptom gets worse (sometimes called ‘breakthrough pain’ or ‘breakthrough symptom’), you will need extra medication. This is usually done with small amounts of medication already prepared by the nurse. Your carer can be taught by the nurse how to give the extra medication. It is important to keep a record of any extra medications that are given. Your nurse will recommend how to keep note of these extra doses.
Looking after Yourself

If you are a carer you know that looking after somebody at home can be very demanding. You will need to look after yourself so that you can continue caring for the person. If you are the person receiving medications via a subcutaneous infusion device you also need to care for yourself.

You might need support from family, friends or people in your community such as from your church or other religious organisation. You will need the support of your GP, your palliative care team and other health professionals. Looking after yourself can be a hard thing to do but here are some ideas for you to think about.¹

- **Accept help.** Family and friends will probably offer to help and they will usually need you to tell them what it is that you need help with. So think about what things you would be happy to let others be involved with. Let them know that maybe they could help with cooking, housework or shopping. It might be helpful to you if they could stay with the person using the driver so you can have some time to yourself or do tasks outside the home. If you are the person with the driver, maybe you would like to go out and leave your family/carer at home or it could be that it takes more than one person to help you leave your home.

- **Feelings.** Anger, resentment or bitterness can be normal at this time. The extra demands on both the person with the driver and the family/carer may leave you feeling anxious, sad or even grieving at this stage. Emotions can be high and sometimes negative feelings will get unloaded on the people who are closest. It is important for you to have a trusted person to talk with and share your feelings. This may be a member of the family, a friend, someone from your church or you may find it better to speak with a member of your palliative care team.

- **Fears.** As family/carer you may worry about leaving the person for even a short time in case they experience suffering or die while you are away. If you find yourself feeling this way it is important to share your fears with someone who understands. Your nurse, GP or palliative care team will help you to manage this fear.

- **Ease up.** Don’t demand too much of yourself. You don’t have to be perfect. Try to work out your priorities, let less important things go for a while, or ask others to help.

- **Physical wellbeing.** Make sure that you have adequate sleep and regular nutritious food. Remember that injuries can happen easily when you are busy or worried. Your palliative care team will talk with you about preventing injury while physically caring for somebody.

- **Time out.** It is important to take time to do things you enjoy. If you feel you cannot leave the patient, ask a friend or relative to stay while you are away. Your palliative care service may have volunteers who can help, or be able to refer you to a Commonwealth Respite and Carelink Centre.

- **Visitors.** They can be very welcome but may stay too long, which can be exhausting. You may need to discuss this with visitors and the patient – be clear that it is the patient’s wellbeing that is most important. Don’t be afraid to remind people that it’s time to leave.

- **Not coping.** It’s not a failure to feel you haven’t met your own expectations or those of others. You may feel you just want it all over and done with. This is natural because of the strain you are experiencing. If you are having problems, speak with somebody from your palliative care team, or your local carers’ organisation.

- **Respite care.** Sometimes you may need a break. Respite care can usually be organised allowing you a complete rest from the daily demands of care. Your GP, palliative care team, or Commonwealth Respite and Carelink Centre can help. It is usually necessary to plan well ahead for long respite care.

- **When it’s all too much.** Sometimes the demands of caring for somebody at home just become too much. Talk with your visiting nurse, your GP or palliative care team. Finding care that suits you may involve the physical care being given by paid workers allowing you time to give important emotional and personal support.