

Information for people living with a terminal illness and those close to them

Introduction

Introduction

A syringe driver (or syringe pump) is a small device used to give medicines that help manage symptoms. It can help with symptoms like pain, sickness, fits, agitation and shortness of breath.

We know lots of people feel nervous about having a syringe driver. If you have any questions or worries, speak to your doctor or nurse. You could also contact our free Support Line on **0800 090 2309*** or email **support@mariecurie.org.uk**

We have a short video about what it's like to have a syringe driver – visit <u>mariecurie.org.uk/</u> <u>syringe-drivers</u>

Pages 3, 6, 7, 9, 11 and 13 of this booklet include images of syringe drivers and some of the equipment used to set them up. If you'd prefer not to see these, you might like to skip these pages.

If you're uncomfortable with needles, it might be helpful to know we do not include any photographs of these. But there are a few images showing the equipment they're attached to.

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What is a syringe driver?

What is a syringe driver?

A syringe driver is a small battery-powered pump. It gives a steady flow of medicines through a small tube just under the skin on your arm, leg, tummy, or back. Medicines in syringe drivers are used to help manage symptoms.

If you're moving around, you can carry your syringe driver with you. Your nurse may give you a bag for the syringe driver, or you might like to use your own.

Syringe drivers can help manage symptoms at any stage of treatment. It's important to know they are not only used towards the end of life. Go to page 12 if you would like to read more about this.

There are different types of syringe drivers. Here are some examples of what your syringe driver might look like:





Why are syringe drivers used?

There are lots of reasons someone might use a syringe driver. For example, it might be helpful:

- if you're being sick or feel sick regularly
- if you find it difficult or impossible to swallow medicines
- as an alternative to having lots of injections
- if your body cannot absorb medicines properly
- if you are more sleepy and cannot swallow medicines
- if your symptoms are not being managed by medicines you're taking in other ways, such as tablets.

Your doctor or nurse should explain why they have suggested a syringe driver. They should also give you the chance to ask questions and talk about any concerns you have.

Although syringe drivers are often used towards the end of life, they are not only used at this stage. They can be useful for managing symptoms at any stage of your illness.

Medicines in syringe drivers

Medicines in syringe drivers

Medicines in syringe drivers are used to treat symptoms including:

- pain
- feeling sick and being sick
- agitation
- fitting (also called seizures)
- noisy breathing caused by a build-up of mucus in the throat and airways
- shortness of breath (also called breathlessness).

Your doctor or specialist nurse will prescribe the medicines best suited to manage your symptoms.

Your syringe driver might give you different medicines at the same time if you have more than one symptom.

All medicines come with possible side effects. Your doctor or nurse should talk to you about these. Speak to them or contact your local pharmacist if you have any questions about your medicines.

Visit **mariecurie.org.uk/syringe-drivers** for more information about medicines used in syringe drivers.

Setting up a syringe driver

Your nurse will set up your syringe driver. Not every nurse will do this in the same way, but these steps might help you know what to expect:



1. Your nurse will put your medicines into a syringe, which goes into the syringe driver.



2. They will place a very small needle just under the skin on your arm, leg, tummy, or back.

Usually the needle is used to place a very small tube just under your skin. It's then removed as soon as the tube is in place.

Sometimes they might use a needle that gets left in place. You should not be able to feel it, as it's very short and thin.

Setting up a syringe driver



3. Your nurse will put a clear dressing over the small needle or tube, to help keep it in place.



4. They will use a long tube to connect the syringe driver to the small tube under your skin.



5. They will switch the syringe driver on, which pushes the medicines through the tubes, and into your body.



6. A green light will flash when the syringe driver is giving you your medicine.

The syringe driver will often be kept in a clear locked box, to protect it from being damaged.

Syringe drivers have a small screen. This shows how much medicine you are being given, and how long it will take.

Your nurse will usually top up or change your medicines once every 24 hours. And they will usually change the tubes every three to seven days. They may change the tubes more often, if you have changes to the skin around where the tube goes in.

You may feel a little scratch when your nurse puts the needle under your skin. After that, having a syringe driver should be painless.



Using the shower, bath, and toilet

Using the shower, bath, and toilet

You can have a shower or bath when using a syringe driver. But the syringe driver is not waterproof, so you'll need to take care to keep it dry. For example, you could put it in a plastic bag on a stool next to the bath or shower cubicle.



You should also try and keep the clear dressing clean and dry. If you get this wet, gently pat it dry and check it's still in place. If it's coming off, contact your nurse for advice. They may change the dressing on their next visit. Ask your nurse if you need advice on keeping the syringe driver or dressing dry.

When you go to the toilet, you can put the syringe driver in a bag and take it with you.

If you get the syringe driver wet or drop it in water, contact your doctor or nurse as soon as you can.

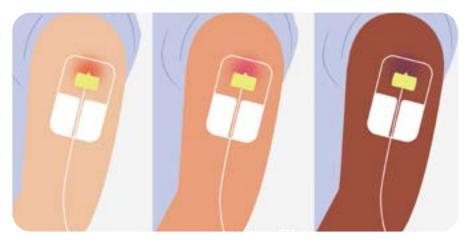
Things to be aware of

Changes to the skin

Check the skin around the tube regularly. Tell your doctor or nurse if you have any swelling, discomfort, or changes in colour.

Colour changes to look out for:

- On lighter skin tones there might be redness.
- On darker skin tones, the skin might be a different colour to the surrounding area (usually darker).



If you still have symptoms

It can take at least three to four hours for medicines in a syringe driver to reach a steady level in your body. This means you might not feel an effect straight away. How long it takes is different for each medicine – your doctor or nurse should be able to tell you more about this.

Things to be aware of

Your doctor or nurse may give you an extra dose of medicine if your symptoms:

- are not manageable while the medicines reach a steady level in your body
- temporarily come back while having a syringe driver.

This is sometimes called a **breakthrough dose**. This may be given as an injection, or a tablet or liquid that you swallow.

The doses in the syringe driver can be adjusted over time to meet your needs.

If the alarm goes off

Syringe drivers have an alarm to tell you when something is not working as it should. For example, if the battery is low, or if there's a blockage. A blockage can sometimes happen if you accidentally lie on one of the tubes.

If the alarm goes off or the syringe driver stops working, try not to worry. Contact your doctor or nurse as soon as you can. They will arrange to visit you and fix the cause of the alarm.

Below is an example of what you might see on the syringe driver when the alarm sounds.



Taking care with your syringe driver

Syringe drivers are safe, reliable and do not need a lot of care. But there are some things to take extra care with:

- Try not to get the syringe driver wet or drop it in water.
- Try not to drop the syringe driver.
- Try not to pull the tubes out take extra care when washing and dressing.

If any of these things happen, try not to worry. Contact your doctor or nurse as soon as you can, and follow their advice.

Worries about how long people live with a syringe driver

Lots of people ask how long someone will live after having a syringe driver. It's not possible to give a definite answer to this, because people can have a syringe driver at any stage of their illness. They are not only used for end of life care.

Some people use a syringe driver for a short time to manage their symptoms. For example, it can be helpful for taking anti-sickness medicines if someone is having chemotherapy.

Sometimes, with the guidance of doctors and nurses, syringe drivers are stopped. People can then switch to different ways of taking medicine, such as tablets or liquids that you swallow, injections, or patches.

Some people also worry that having a syringe driver can speed up dying. But it's important to know there is no evidence for this.

Worries about how long people live with a syringe driver

When someone is already approaching the end of their life, they may be more sleepy, and find it hard to swallow medicines. So having a syringe driver can be the easiest way to give someone the medicines they need to feel comfortable at this stage.

It's important you have the information you need to feel comfortable with your care. Your doctor or nurse should explain why they have suggested a syringe driver. They should also give you the chance to ask questions and talk about any concerns you have.

You might find it helpful to write down any questions you have before you see them. You could use the **Your notes** section at the back of this booklet (see page 20).



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Worries about needles

If you have a fear of needles, or struggle with how they feel, you are not alone.

It's a good idea to speak to your nurse before they come, and let them know about any worries you have. They might be able to suggest things they could do to help you feel more comfortable.

There may be specific adjustments you would find helpful. For example, you could ask your nurse if they could do any of the following:

- Use something to numb the skin so you cannot feel the needle.
- Hide the needle when they are preparing the syringe driver.
- Explain what the needle is for and where it will go (some people feel more relaxed if they understand exactly what will happen).
- Book to spend more time with you than usual. This might help if you need more time to ask questions, prepare for the needle, or get used to the tube.

Worries about needles

Here are some things you could try yourself that might help you feel more comfortable:

- Have something with you that helps you relax, for example a stress ball, fidget toy, or some music.
- If possible, laying down or sitting back in the chair might help you feel more relaxed.
- Ask someone to be there to support you, such as a friend, family member or carer.
- Try not to look at the needle when it's being used. Some people like to distract themselves with their phone or a book, or by talking to someone.



Getting support

We know lots of people feel nervous about having a syringe driver, and it's important to know where you can get support.

If you have any worries about your syringe driver, contact your doctor or nurse. If you have any questions about your medicines, you could also contact your pharmacist.

You could also call the free Marie Curie Support Line on **0800 090 2309*** or email <u>support@mariecurie.org.uk</u> They can provide emotional support, or you can speak to an Information and Support Nurse if you'd like practical information.

Marie Curie's Online Community gives you the chance to connect with people in similar situations to you. You may be able to speak with others having a syringe driver, or supporting someone that's having one. Visit <u>community.mariecurie.org.uk</u> to join Marie Curie's Online Community.



How Marie Curie can help

How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line 0800 090 2309*

Email: support@mariecurie.org.uk

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at **mariecurie.org.uk/support**. Open between 8am to 6pm from Monday to Friday, and 11am to 5pm on Saturday.

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want – at home, in hospital or over the phone.

mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago. <u>mariecurie.org.uk/bereavement</u>

* Your call may be recorded for training and monitoring purposes.

Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end. **mariecurie.org.uk/hospices**

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too – from reassurance and practical information to letting them take a break.

mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information available online at <u>mariecurie.org.uk/</u> <u>support</u> or to order at <u>mariecurie.org.uk/publications</u>

About this information

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been developed with people affected by terminal illness, and health and social care professionals.

If you'd like the list of sources used to create this information, please email **review@mariecurie.org.uk** or call the free Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Did you find this information useful?

If you have feedback about this booklet, please email us at **review@mariecurie.org.uk** or call the free Marie Curie Support Line on **0800 090 2309***.

Your notes

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Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit **mariecurie.org.uk/support**

We also have an Online Community where you can share thoughts, feelings and experiences at **community.mariecurie.org.uk**

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it. To donate, visit **mariecurie.org.uk/donate**

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.



Patient Information Forum

