

# UNDERSTANDING YOUR MEDICINES

Practical help  
and guidance on  
medicines



# UNDERSTANDING YOUR MEDICINES

**We hope the contents of this booklet will be helpful to you and your family and friends. This booklet aims to answer questions and provide information on medicines. Your clinical team will be happy to offer advice and support on management of pain and other symptoms. This may involve advice or input from other members of the team if medicines on their own are not suitable for you.**

Although you are receiving this booklet, it's possible that you may not need any of the medication listed in here. When you do receive medication, please ensure you read the patient information leaflet that is provided.

**Do not share your medicines with anyone else – they have been prescribed for only you.**

Sometimes a healthcare professional may recommend that you take an off-label or unlicensed medicine. Off-label use means that the medicine isn't licensed for treatment of your condition, but it will have a licence to treat another condition and will have undergone clinical trials for this.

## OTHER INFORMATION BOOKLETS AVAILABLE FROM ST CHRISTOPHER'S

- *Planning ahead: what you need to know*
- *Welcome to St Christopher's.*



For further information on these topics, please visit [nhs.uk/conditions/medicines-information](https://www.nhs.uk/conditions/medicines-information) or scan the QR code.



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# MORPHINE AND OTHER OPIOIDS

Opioids are strong pain-killers and usually relieve pain effectively. They are also used to manage breathlessness in certain situations. The most widely-known opioid is morphine. Others include oxycodone, fentanyl and codeine.

Opioids work well for many types of pain and are most commonly used after surgery and for cancer pain. With a few exceptions, they are **not** usually recommended for chronic non-cancer pain.

## WHEN ARE OPIOIDS USED?

If pain is severe and hasn't responded to regular paracetamol, a weak opioid, usually codeine, can be added. Codeine is similar to morphine but is about one tenth as strong. Sometimes for convenience you can take codeine and paracetamol together in one tablet called co-codamol.

If this doesn't help the pain, you may be offered a stronger opioid such as morphine. Opioids can be given at any stage during an illness. If the pain improves, the dose may be reduced and sometimes stopped. If the pain is due to cancer, it's likely you'll need the opioid long term.

## WHAT OTHER MEDICINES ARE USED TO MANAGE PAIN?

Other medicines and treatments can be used at the same time as opioids because pain may have more than one cause.

For example, if the pain is being caused by damage to a nerve, opioids may not be so effective and other medicines may be needed in addition or instead.

Most people will have good pain relief with opioids once the dose is right for them, although this can vary widely between people.

## HOW TO TAKE OPIOIDS

There are several ways to take opioids. They're available as:

- tablets
- capsules
- liquids
- injections
- skin patches.

Your clinical team will work with you to find the option that works best for you.

## IMMEDIATE-RELEASE (IR) OPIOIDS

These usually start to work within 20 to 30 minutes and their effects last about four hours, or sometimes longer. They may be used to work out the right dose for you as it can be increased or decreased quickly.

IR opioids can also be used 'when necessary' to fit with the pain. If the pain is there all the time, IR opioids will need to be taken several times a day. For convenience, once a stable dose has been established, your team will try to move you to a long-lasting opioid.

IR opioids include:

- morphine (liquid or tablets)
- oxycodone (liquid or capsules)
- fentanyl (sublingual 'under the tongue' tablets), which last for a shorter time.

You may find it helpful to keep a note of what extra pain relief you have taken and when it was required so that your clinical team can work out the dose.

## **MODIFIED-RELEASE (MR) OPIOIDS**

These are designed to keep a steady level of medication in your body and hopefully reduce the amount of IR opioid you need. They are designed to be effective for 12 hours or longer. It's important to take MR opioids at regular times – perhaps 9am and 9pm – to ensure the pain is controlled evenly.

MR opioids include morphine (tablets or capsules) and oxycodone (tablets).

In most cases, you'll be offered an MR opioid that works 'around the clock' and given another IR opioid to take for extra pain relief when required. You'll be given instructions for how and when to take these different opioids.

## **OPIOID PATCHES**

Fentanyl or buprenorphine opioid skin patches work by absorbing the drug through the skin. They are changed every few days (depending on the type prescribed). These can be very convenient when pain stays at the same level. They can be useful for patients who have difficulties with swallowing medicines, or may have a problem with absorption.

## **INJECTIONS**

Injections for symptom relief are usually given under the skin (subcutaneous). They work within 10 to 15 minutes and can last up to four hours.

If you have problems taking medicines by mouth then you may be offered opioids by injection or by using a syringe pump which gives the opioid under the skin continuously over 24 hours. We'll discuss this with you in detail if you need a syringe pump.

Injections include morphine, oxycodone and alfentanil.

## MANAGING YOUR OPIOIDS

Keep an up-to-date list of your opioids (and other medicines) to show other doctors.

Whenever you start to take opioids, especially at first, your clinical team will check with you regularly so that a dose is found that is right for you and your pain.

If you're unsure about any of your medications then please ask your clinical team. We're always happy to explain what medications you're taking and why.

## SIDE EFFECTS

All medicines have side effects. Please do read the patient information leaflet that comes with your medication or speak with a member of your clinical team for a full list. Some of the most common side effects with opioids are:

- **Nausea** (feeling sick) This usually wears off after a couple of days as your body gets used to the opioid
- **Constipation** This is a very common and preventable side effect of opioids. If your team recommends an opioid they will recommend a laxative in case you need it. It's likely that you'll need to continue taking it regularly whilst taking opioids

- **Drowsiness** Some people feel drowsy and find it difficult to concentrate when they start taking opioids, or when their dose increases. As with other medicines, you should avoid manual tasks that need concentration if you feel like this. You're likely to find that this effect wears off within a few days and you should be able to return to your normal activities.

## DRIVING

Although it's an offence to drive with high levels of drugs in the body, the police are aware people can be prescribed these medications and be taking them appropriately. If you're prescribed these medications, you are legally allowed to drive as long as you can show that:

- You have been prescribed them and followed advice on how to take them by a healthcare professional
- They are not causing you to be unfit to drive even if you are above the specified limits.

When you first start taking opioids or if your dose is changed, be aware of how drowsy or dizzy you are feeling before deciding to drive.

Further information is available at [gov.uk/drug-driving-law](https://www.gov.uk/drug-driving-law). You may also want to inform your insurance company.

## COMMON QUESTIONS

### Will I get addicted to opioids?

When they are taken appropriately for pain in life-limiting conditions, they almost never cause addiction. Many people stay on the same dose for a long time but it is also common for the dose to increase gradually. If the pain improves, the opioid may be reduced.

### Do opioids shorten life?

Research shows that they do not. In fact, they can improve quality of life.

### Will the opioids get less effective if my pain gets worse?

There is no maximum dose for opioids so the dose can be slowly and carefully increased if your pain changes. Any dose changes should be discussed with your clinical team.

Sometimes the maximum dose is limited by side effects which will wear off with time or if the dose is reduced. If this happens, your clinical team will discuss with you a different opioid and/or a non-opioid such as an anti-inflammatory.

### Can I go on holiday if I am taking opioids?

It's possible to travel to most places in the world with opioids although the rules are different in some countries. Ask for advice from your clinical team or pharmacist, and check online at [gov.uk/take-medicine-in-or-out-uk](https://www.gov.uk/take-medicine-in-or-out-uk).

### Should I stop taking opioids?

We wouldn't advise you to stop taking opioids without speaking to your clinical team first.

### Should I increase my dosage?

You shouldn't take more than the dose you've been advised to take. Contact your clinical team for any advice or support.

### When should I call for further advice?

If you're experiencing a serious or new side effect, a side effect is getting worse, or if you've accidentally taken too much, then contact St Christopher's or your GP. Very occasionally, you may need to call an ambulance if your side effects get worse, or if you've accidentally taken too much. Keep your medicine containers with you so you can show them what you've been taking.

### Safe storage and disposal

Opioids are 'controlled drugs' so there are additional safety measures with prescribing and supplying them. You or a representative may be asked for identification when collecting a prescription. Store all your medicines in a safe place, out of the reach of children and return any unwanted medicines to your local community pharmacy. If you are admitted to one of our wards, we may ask your family to take any unwanted medicines, including opioids, to a pharmacy for safe disposal.



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# CONSTIPATION AND LAXATIVES

## CONSTIPATION AND ITS MANAGEMENT

Constipation (having trouble pooing) is a common problem, especially if you're ill. Being constipated is a problem that shouldn't be ignored as it can lead to severe discomfort. It can mostly be managed effectively with advice and/or medication. Don't wait – constipation is easier to sort out if treated early.

You can visit [nhs.uk/conditions/constipation](https://www.nhs.uk/conditions/constipation) for further information on constipation, its symptoms, causes and tips (including changes to your diet) on how to prevent and treat it.

If you don't have access to the internet, speak to a member of the St Christopher's team who can provide you with a printed copy.

Generally, people poo every one to three days, without straining, but this frequency may vary, as we're all different. Your clinician will ask you what your bowel habit was before you became unwell.

It's important to know that you should poo even if you are eating little or not eating at all.

Common medications that can cause constipation:

- **Painkillers** Most commonly opioids (see previous section), but generally speaking all painkillers except for paracetamol

- **Antisickness** Such as cyclizine, ondansetron and haloperidol
- **Supplements** Iron and calcium, etc
- **Other** Antacids (medications for indigestion and heartburn), antidepressants (medications for low mood), water tablets and some blood pressure tablets etc.








## LAXATIVES

If you've been prescribed any of the medications mentioned in this booklet (but especially opioids, like codeine, morphine or oxycodone), you should also have a laxative (a remedy to help you open your bowels) prescribed. If you don't, please ask for it.

There are many different laxatives available (you can find more information at [nhs.uk/conditions/laxatives](https://www.nhs.uk/conditions/laxatives)), but if you are taking opioids, it's best to avoid taking ispaghula husk (Fybogel, Ispagel).

Your clinician will normally prescribe an initial dose (recommended quantity) of a specific laxative, but you may need to take less or more depending on how often you're pooing and the consistency of your stools/poos.

If you have not opened your bowels for a few days, you may need to increase the dose of your laxatives.

Type	Image	Description
1		Separate hard lumps, like nuts (hard to pass)
2		Sausage-shaped but lumpy
3		Like a sausage but with cracks on the surface
4		<b>Ideal type</b> Like a sausage or snake, smooth and soft
5		Soft blobs with clear-cut edges
6		Fluffy pieces with ragged edges, a mushy stool
7		Watery, no solid pieces – entirely liquid

You should seek the advice of a healthcare professional if the prescribed dose of your laxative is not working for you, however, it's generally safe to increase them by yourself as a first step.

At the end of this section you'll find a table with a list of the most common laxatives and general advice on how to increase them.

### Additional tips

- Drink plenty of fluids during the day (if you're unable, try frequent small sips of fluids)
- Increase your fibre intake if you can – prune juice is also a good option
- Try to mobilise more if you can (even small movements help)
- Lean forward when you're seated on the toilet (or commode) and try to use a small footstool under your feet
- Don't stop laxatives completely if you remain on opioids
- Consider keeping a diary of your bowel movements
- Your clinician may ask you what your stools look like, so you can find a helpful chart on the next page. Knowing your stool type will help with treatment

- The ideal stool is Bristol type four. Type two and three are OK temporarily but laxatives may need a review. Please discuss with your team if you are worried.

### **Help with laxatives**

On the next page you can find a table of the most common laxatives. It contains the name of the laxative, how long (on average) it takes for the laxative to work, and general advice on how to increase them by yourself.

Two examples (marked by different colours) are provided for each laxative. Choose the one that is relevant for you, depending on your current prescribed dose.

If you're taking two or more laxatives together, you can just increase one of them.

If you have doubts, or you're still constipated after following this advice, please contact St Christopher's or your GP.

Name of laxative	How long does it normally take to work?	Example one of current prescribed dose	New dosage if bowels not opened after two or three days	Example two of current prescribed dose	New dosage if bowels not opened after two or three days
<b>Senna</b> (Senokot) tablets (a liquid form is also available)	8-12 hours	Two tablets (15mg) once at night	Two tablets (15mg) morning and evening	Two tablets (15mg) morning and evening	Three tablets (22.5mg) morning and evening
<b>Bisacodyl</b> (Dulcolax, Entrolax) gastro-resistant tablets	6-12 hours	One tablet (5mg) once at night	Two tablets (10mg) once at night	Two tablets (10mg) once at night	Four tablets (20mg) once at night
<b>Docusate sodium</b> (Dioctyl, DulcoEase) capsules (liquid form also available)	12-72 hours	One capsule (100mg) twice a day	Two capsules (200mg) twice a day	Two capsules (200mg) twice a day	Two capsules (200mg) three times a day (maximum dose)
<b>Lactulose</b> oral solution (only liquid form available)	Two to three days	5-10 mL twice a day	10-15mL twice a day	10- 15mL twice a day	15mL three times a day
<b>Macrogol 3350</b> with potassium chloride, sodium bicarbonate and sodium chloride (Movicol, Cosmocol, Laxido)	One to three days	One to two sachets per day	Two to three sachets per day	Two to three sachets per day	Three to four sachets per day



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# 'JUST IN CASE' MEDICATIONS

## WHAT ARE 'JUST IN CASE' MEDICATIONS?

Sometimes your clinical team will request for a GP to supply you with a small box or bag of medicines to keep at home, just in case you need them for symptoms you might experience in the future.

Keeping these medications at home avoids any delays getting them prescribed and collected from a pharmacy, especially at night or over the weekend.

These may be in a tablet or liquid form but are most often in injectable form.

## WHICH MEDICINES MIGHT I BE GIVEN?

The medicines supplied could include:

- **Morphine or other opioid** To reduce pain and/or shortness of breath
- **Midazolam** To reduce restlessness, distress or agitation. It is also commonly used to manage seizures (fits)
- **Haloperidol or an alternative drug** To help with sickness or feelings of sickness (nausea) and also used for hallucinations and delirium
- **Glycopyrronium** To reduce the saliva or moisture in the throat or chest that may cause noisy breathing.

You may not have all these medications supplied and you may have some not mentioned in this list. It will depend on your condition and symptoms. Your team will explain your medication to you.

## WHY ARE THEY PRESCRIBED IN INJECTABLE FORM?

You may be taking medicines as tablets or liquids by mouth to manage your symptoms. Your team wants to make sure that if it becomes difficult to take your medicines by mouth, or if you're vomiting, that you can still receive the medication you need.

An injection just under your skin is an alternative way for you to be given the medicine. This can be given at any stage of your illness.

## WHAT HAPPENS IF I'M TAKING OTHER MEDICINES?

Your team will talk to you about your other regular medicines if you're finding it difficult to carry on taking them.

Some of them might be stopped completely, or continued by injection instead. Some medicines may need to be adjusted depending on how you are feeling and sometimes an alternative medicine might be used instead.

## WHO WILL GIVE ME THE INJECTIONS?

A district nurse or one of the Community Palliative Care Team will give you these medicines to make sure your treatment is effective and safe. Occasionally, it may be appropriate for you or someone close to you to administer injections. For more information about this ask your clinical team.

## HOW WILL I RECEIVE THE INJECTIONS?

Instead of having an injection each time you receive one of the medicines, the nurse may put a very small plastic tube (cannula) just under your skin which usually stays in place for about three days and medicine can be given through it.

Sometimes the medicine you need is given continuously over 24 hours using a battery-operated syringe pump. These are used on our wards and in people's homes.

Staff will visit you regularly to check the pump and to renew it each day. The medications will be adjusted according to your needs.

## WILL I EXPERIENCE ANY SIDE EFFECTS WITH THESE MEDICINES?

In the last weeks and days of someone's life, it's common for them to sleep more and find talking more difficult. This

is regardless of any medication they are on, although some medication may increase drowsiness.

For more about what dying looks like, please see our booklet *Planning ahead: what you need to know* in which we describe the stages of the dying process. You can ask a clinician for a copy of this booklet or download it from our website at [stchristophers.org.uk/booklet-planning-ahead](http://stchristophers.org.uk/booklet-planning-ahead).

All medicines can have side effects. If you need any of these medicines your team will discuss the possible side effects with you, and look at ways to help prevent them. You can always include a friend or family member in this discussion if you want. Written information is also available in the patient information leaflet that comes with the medicines.

Please talk to your team if you are concerned and they will find an alternative plan if the medication you are taking does not suit you.

## HOW SHOULD I STORE THESE MEDICINES?

Often you'll be given the medicines in a small brown cardboard box or a bag. Inside there will be:

- needles
- syringes

- a sharps bin
- paper forms to record what you have been given by your clinical team.

If you've been discharged from hospital they may have given you a supply of them in a pharmacy bag. As with any medicine it's important to follow these important safety steps:

- Store at room temperature unless the instructions state to store in a fridge
- Store in a safe place out of the reach of children
- Do not share your medicines with anyone else – they have been prescribed for only you.





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# OXYGEN

Oxygen is vital for our bodies and having low oxygen levels can make you feel unwell. There are many causes of low oxygen levels, for example, chronic lung diseases, pneumonia and blood clots in the lungs.

Oxygen is a medicine and must be prescribed by a doctor or specialist respiratory nurse. Using oxygen will not make you 'dependent' on it.

Oxygen is not very successful at treating feelings of breathlessness. Also, feeling breathless does not always mean oxygen levels are low. Please see our booklet *Managing your breathlessness* for more information.

## HOW WILL I HAVE OXYGEN AT HOME?

If you have been an inpatient on one of our wards and need oxygen at home our doctors will prescribe this for you.

If you need oxygen when you are already at home, this is almost always prescribed by the respiratory (lung) team. Neither your GP nor St Christopher's can prescribe oxygen unless there are exceptional circumstances.

If you're likely to need oxygen for more than a few hours a day, the oxygen will usually be given through a machine called an oxygen concentrator, which will be installed in your home by an oxygen supplier.

The concentrator is plugged into the mains electricity supply and comes with long tubing so that you can move around your home, while still benefiting from the oxygen.

You will be able to claim back the money spent on electricity to power the concentrator directly from the oxygen supplier by completing the form that you will be given when the concentrator is installed. If you have any issues or concerns around this you can speak to our Welfare team.

The oxygen supplier will also provide a large static back-up cylinder in case of power cuts. If you need a portable cylinder for going out, this can also be arranged.

## HOW MUCH OXYGEN WILL I NEED?

This can vary; some people use it for short periods, while others may need it 24 hours a day. Long-term oxygen therapy is given for some types of chronic lung conditions and is usually started by a hospital.

## CAN I TRAVEL WITH OXYGEN?

Yes, provided you have discussed your overall fitness to travel with the team looking after you. This is particularly important if you're planning to fly. If you wish to travel please also contact your oxygen supplier.

## CAN OXYGEN BE HARMFUL?

Oxygen is very safe when used properly. It's important not to adjust the flow rate of your oxygen concentrator or cylinder as this will have been prescribed for you after careful assessment. If you're concerned about breathlessness contact your St Christopher's nurse, GP or respiratory nurse as soon as possible.

For further information you can read the NHS website page on oxygen at [nhs.uk/conditions/home-oxygen-treatment](https://www.nhs.uk/conditions/home-oxygen-treatment).

## OXYGEN SAFETY

Do not smoke (even e-cigarettes can be dangerous and are not permitted on hospice wards) or let anyone smoke near you or the oxygen, because this creates a fire risk to you and other people. There are cases of people suffering severe burns to the face and lips when they smoked near their oxygen. Even if the oxygen is turned off, the air in the room, your clothes and your bedding will have more oxygen in them because of the concentrator, and could catch fire more easily than usual.

Oxygen is denser than air and can remain in clothing and bedding up to 30 minutes after it has been turned off.

Unless there are exceptional circumstances, it will not be possible for you to have oxygen at home if you smoke.

Keep away from naked flames and from heat – stay at least six feet back. Avoid using flammable products like Vaseline or other petroleum-based products, alcohol gel, cleaning fluid and aerosols.

Keep tubing free and oxygen cylinders upright to avoid them getting damaged.



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# SUPPORT WITH YOUR MEDICINES

## WHAT IF I NEED MORE MEDICATION?

Please keep track of your medication and remember to order repeat prescriptions early to ensure you have enough of each. You can do this by contacting your GP.

If you're receiving injectable medicines, then your district nurse will keep a check of how many you have left and request for your GP to prescribe more when needed. If you or the person caring for you notice your supplies are running low, please check with your district nurse that they have ordered more.

St Christopher's does not have a dispensing community pharmacy which means we can only issue medicines in an emergency.

## SUPPORT FROM COMMUNITY PHARMACIES

Your team may recommend support from a community pharmacist to help you with your medicines. For example, visiting you to check your medicines and/or arranging your medicines in a blister pack.

## WHAT SHOULD I DO IF I HAVE MEDICINES LEFT OVER?

Please do not bring unused medicines back to St Christopher's. They should be taken back to your local pharmacy. Explain that they are no longer needed and ask the pharmacist to dispose

of them. If you're unable to do this please tell your clinical team so they can help you.

If you have been given a St Christopher's syringe pump at home this should be returned to the hospice once it is no longer needed. We can arrange for it to be picked up and returned to St Christopher's if it's easier. If you have any questions you can telephone the hospice on **020 8768 4500** for more advice, and you can always discuss this with us.



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# WHO TO CONTACT IN DIFFERENT SITUATIONS

## SELF-CARE

Follow the plan for symptom control and your overall health and wellbeing given to you by your care team.

Make sure you understand the purpose of any medication(s) you are taking. Keep track of your medication and remember to order repeat prescriptions early to ensure you have enough of each medication.

## NON-URGENT

Monday to Friday, 9am-5pm, call St Christopher's on **020 8768 4500** for non-urgent advice – e.g. non-urgent symptom control, non-urgent medication advice or to change the time of an upcoming appointment

Call your hospital team if you have questions about the treatment they are giving you.

Call your GP:

- to order your repeat prescriptions
- if you think you have an infection or new medical problem
- to obtain a referral to other services, such as podiatry, physiotherapist, dietician, optician, community mental health team etc.

Call the district nurse or community matron to:

- get incontinence pads or aids
- arrange to change the dressing on a wound
- obtain equipment or report a problem with faulty equipment
- Call your local pharmacy to:
  - ask questions about your medication
  - arrange prescription deliveries and collections.

Call your care agency, social services or your local clinical commissioning group to discuss issues with funding or provision of care.

## URGENT OUT-OF-OFFICE HOURS

Call St Christopher's on **020 8768 4500** to report:

- an urgent change in physical or psychological symptoms
- a rapid or sudden deterioration in your health.

Call Acute Oncology Services (AOS) to report urgent symptoms related to cancer therapy.

Call **999** to get help in emergency situations, e.g. broken bones, seizures or uncontrolled bleeding.

# PERSONAL LIST OF MEDICATIONS

## MEDICATION

## NOTES, DOSAGES AND SIDE EFFECTS




## MEDICATION

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If you would like this information in a different format, such as audio tape, braille or large print, or in another language, please speak to the Communications Team on **020 8768 4500** or email [communications@stchristophers.org.uk](mailto:communications@stchristophers.org.uk).



### **Sydenham site**

51-59 Lawrie Park Road,  
Sydenham, London SE26 6DZ

### **Orpington site**

Caritas House, Tregony Road,  
Orpington BR6 9XA

Telephone **020 8768 4500**

Email [info@stchristophers.org.uk](mailto:info@stchristophers.org.uk)

   [stchrishospice](https://www.stchrishospice.org.uk)  
[stchristophers.org.uk](https://www.stchristophers.org.uk)

At St Christopher's Hospice, we have a vision of a world in which all dying people, and those close to them, have access to care and support, whenever and wherever they need it.

Operating from two locations, one in Sydenham and one in Orpington, our reach spans a diverse population of approximately 1.6 million people within the five London boroughs of Bromley, Croydon, Lambeth, Lewisham and Southwark.

Our ambition is to help people live well until they die, and support those affected by the death of a friend or relative. Each person is unique, so we ask "What matters most?" and then tailor our care to meet social, emotional and spiritual needs, as well as manage physical symptoms.

Everyone should have access to the best care at the end of their lives. We provide this through a mix of expert clinical care, support at home, research and education, and strategic partnerships with other organisations that have the same aspiration. We are proud that last year we provided care and support to 5,785 patients, 1,358 carers and 445 children across south east London.

We need to raise over £16 million every year to continue to care for people when it matters most. This would not be possible without the support of our local communities, our donors, our staff and our volunteers, so a huge thank you for your support, from us all.