



# Supporting care at home in the last days of life



Due to changes in your relative or friend's condition, we believe that the person you care about is now dying and entering the last days of their life. A plan of care to support your relative or friend will be put in place and this leaflet aims to explain what will happen in the days going forward.

**NHS**  
Sheffield

Clinical Commissioning Group

## What care will be provided at home?

At home your relative or friend will be under the care of their GP and district nurse teams 24 hours a day, 7 days a week. St Luke's integrated community team provides a 7 day service, 9am - 5pm, offering specialist support and advice including face-to-face assessments.

Your GP, district nurse and the St Luke's integrated community team will develop a plan of care to meet your relative or friend's needs and, with their permission, will discuss this with you. This will include consideration of their needs around food and drink, and supporting their physical, mental and spiritual needs. If you are aware of any particular needs that they might have, please talk to the team about this. The team will regularly review your relative or friend's care plan and will make changes as and when their circumstances or wishes change. Any changes to the plan will be discussed with you. Please ask a member of the team if you have any questions about your relative or friend's care.

## Looking after your relative/friend at home

The plan of care at home could include equipment and personal care. This can be arranged before discharge from hospitals or St Luke's, or from home as your relative or friend's needs change. Depending on your relative or friend's needs it may be possible to arrange up to 24 hour care. Your GP will be able to arrange this for you.

You can continue to provide personal care if you wish, and the team caring for your relative or friend can guide you through this. This could include activities such as washing and turning if you are happy to do so. Please do speak with a member of the team if you feel your relative or friend's care needs are not being met.



## Eating and drinking

Towards the end of life your relative or friend's eating and drinking habits may change. It is normal for them to eat and drink less, and the types of food they want may change.

The team caring for your relative or friend will assess if they are experiencing any swallowing problems and will offer dietary advice such as having a soft diet, eating ice lollies or drinking smoothies. They will also advise you on giving mouth care to keep their mouth and lips moist.

## Medications

### Giving medication

You may give oral medication to your relative or friend. Towards the end of life your relative or friend may have difficulty swallowing oral medications. Please let the team know if this becomes the case. The team will review and change your relative or friend's medication when necessary, as well as explaining any changes in their medication and new plans of care.

### Prescriptions

To help speed up the delivery of medications, there may be times when we ask you to collect prescriptions on your relative or friend's behalf. The team can support you with arranging for prescriptions to be collected or delivered from your chemist, although there may be a charge for this. Some medications can be difficult to collect locally and on occasions the team may need to redirect you to an alternative pharmacy. Opening times of pharmacies vary across the city. Make sure that you have enough of your relative or friend's medications, in case they need them outside normal opening hours.



## Safe storage and disposal of medications

### How should medications be stored?

Medicines should always be stored in their original containers. Any special instructions e.g. to keep in the fridge will be written on the pharmacy label. They should be stored in a secure dry place within the home, out of direct sight, away from sunlight and extreme temperatures and out of the reach of children and pets.

## Managing symptoms at the end of life

### Pain

This does not always occur. Should your relative or friend experience pain the team can give medication to help them feel more comfortable. Often this is given by injections or a syringe driver (a small pump that delivers medications continuously). Sometimes pain can be complex and it may take multiple assessments to try to manage this.

### Confusion, restlessness and agitation

These symptoms can take many forms and can be normal at this stage. Your relative or friend may be confused about time and place, and may be unable to recognise familiar faces. This can be a difficult experience for you. Please talk with the team if you are finding it so. They will assess the cause and try to manage these symptoms.

### Difficulties with going to the toilet

For many reasons, people at this point in their life can lose control of their bowel and bladder function. The team will make sure that your relative or friend's comfort and dignity is maintained, and can offer pads and catheters to help manage these symptoms.

### Nausea and vomiting

Should your relative or friend experience nausea (feeling sick) or vomiting (being sick), the team will assess the cause and will try to manage these symptoms.

## Problems with breathing

At the end of life, breathing can become irregular, noisy and can stop for short periods at a time. This is normal at this stage and does not mean that your relative or friend is uncomfortable. The team can try to ease these symptoms and help to make their breathing better.

## Changes in circulation

You may notice that your relative or friend's skin becomes blotchy and/or their arms and legs feel cool. This is normal at this stage and is due to slowing circulation.

## Care after death

### Who to contact

Following the death of your relative or friend, you will need to arrange for a health care professional to verify the death. This does not have to be done by a GP who knows your relative. During normal opening hours you should contact your relative or friend's GP. If the death occurs out of hours you should contact the NHS 111 Service/Out of Hours GP on 111. Depending on the day and/or time it may be your family GP or a clinician from the out of hours services who will visit.

Once the death has been certified you may contact the undertaker in your own time. The death certificate will be issued by your relative or friend's usual GP; once this is completed you can then make an appointment to register the death at the registry office. In some cases, such as if the death is unexpected, the doctor may need to inform the coroner and a post mortem undertaken before your relative or friend's body can be released.

The district nurse will be able to help and assist you with arranging the collection of any equipment. Please be aware that this may not happen straight away and it could be some time after the death before the equipment is collected.



## What should I do with any remaining medications that are no longer needed?

Prescribed drugs are the property of the person and remain so even after they have died. The responsibility for the safe disposal of medications left in the home then passes to the family or next of kin, and we usually ask a relative or friend to return any remaining medications to the pharmacy. Please do not dispose of medication down the toilet or in the bin, as this can cause harm to the environment and public.

The district nurse and your local pharmacy will be able to support you with the safe disposal of needles and syringes. Please discuss with the district nurse if you have any specialist equipment such as syringe drivers that need collecting and they will be able to assist you with their return.

## What should I do with any remaining prescription slips, files and documents?

Any prescription slips that were given to your relative or friend but not needed should be returned to their GP practice. If they received repeat prescriptions from a local pharmacy, please let them know that they have died, to avoid further deliveries of medication. The district nurse or care agency will collect any remaining files or documents.

## Help and support

Caring for you and your relative or friend is very important to us. We understand that this situation might be frightening for you, but you are not on your own. A wide range of organisations are on hand to help and support you. Should you have any questions or concerns at any time, please contact any of the organisations listed at the end of this leaflet for further advice.



## St Luke's bereavement support

If your relative or friend has been under the care of St Luke's, a member of the bereavement service will contact you following their death either by letter or telephone. If you need help before this time please contact St Luke's on 0114 236 9911 or alternatively call into Clifford House, Ecclesall Road South, Sheffield, S11 9PX, where a member of the team will be able to advise you on the various support services available across the city. Clifford House opening hours: Tuesday - Thursdays, 10am - 4pm

## Who should I contact?

### St Luke's

0114 236 9911

Cares for adults throughout Sheffield who have terminal illnesses and offers help with managing symptoms, alleviating pain and improving quality of life.

Service is available 9am - 5pm, 7 days a week.

### Single Point of Access (SPA)

0114 226 6500

For advice on available services. The district nurse service is available 24 hours a day.

### NHS 111 Service/Out of Hours GP

111

NHS non-emergency number for assessment of symptoms and advice on medical care.

Service is available 24 hours a day, 365 days a year.



## Adult Social Care (Sheffield Health and Social Care NHS Foundation Trust)

0114 271 6310

Offers care and support to people living with an illness, and can provide help with washing and dressing, and preparing and eating meals.

## Age UK

0114 250 2850 • [enquiries@ageuksheffield.org.uk](mailto:enquiries@ageuksheffield.org.uk)

Offers a range of information, advice and support.

## Cruse Bereavement Care

0114 249 3328 • [sheffield@cruse.org.uk](mailto:sheffield@cruse.org.uk)

Offers face-to-face, telephone, email and website bereavement support.

## Wicker Pharmacy

0114 272 7676 • [pharmacy@wicker.co.uk](mailto:pharmacy@wicker.co.uk)

For advice on medications.

Monday - Saturday - 8:30am - 10pm

Sundays/bank holidays 10am - 8pm

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[www.stlukeshospice.org.uk](http://www.stlukeshospice.org.uk)

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This leaflet is produced by St Luke's Hospice, Sheffield, in conjunction with NHS Sheffield Clinical Commissioning Group.

St Luke's is Sheffield's only hospice, a charity, and provides specialist care, support and advice for patients and families at home, as well as in its specialised centres.

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