

## To be completed by nursing team in patients who are to be discharged home

Referrals have been made to the following people who have been asked to contact you :

### USEFUL CONTACTS

	Yes/No	Name/ Organisation	Contact Number
Care Agency			
GP			
District Nurse			
Hospice			

Ashgate Hospicecare Advice line (7days per week 9am-5pm)	Tel: 01246 565026
Helens Trust <small>(A local charity that helps people to stay at home when they have a terminal illness)</small>	Tel: 01629 812759 <a href="http://www.helenstrust.org.uk">www.helenstrust.org.uk</a>
Derbyshire Carers association	Tel: 01773 743355 Fax: 01773 512288 Email: <a href="mailto:info@derbyshirecarers.co.uk">info@derbyshirecarers.co.uk</a>
Carers Liaison Officer Rebecca Cowley Chesterfield Royal Hospital	Tel: 07825532952 Tel :01246277271 Bleep 097
Marie Curie <small>(A charity which supports patients in their own homes)</small>	Tel: 08450567899

*Care at home when someone is  
in the last hours and days of life*

Information and support for  
families and carers



Affix patient Sticker or

Name: .....

DOB.....

Hosp Number.....

Ward	
Date of discharge	
Completed by	
Designation	
Date & time	
Signature:	

This leaflet has been designed to provide information about the changes that may happen, and the care and support that is available when we believe someone is in the last days of their life. It will hopefully answer some of the questions you may have, but please ask the doctors and nurses who visit if there is anything you do not understand or you have any more questions.

It is important to know what to expect when someone nears the end of life. Nothing can take away the feelings of pain and loss, but having information can help you to cope during this anxious and difficult time. For most people dying is a very peaceful process. Some of the changes may be distressing to you and this information will help you to recognise these changes and reassure you that they are normal.

The dying process is different for every person. It is always difficult to know how long someone has left, sometimes people die very quickly with little warning and other people become gradually less well over several days, you understandably are likely to find it difficult to cope with this uncertainty.

Space to make notes:

## The Final moments

For most people the final moments are peaceful.

Breathing becomes slower and more irregular with long gaps in between breaths. Finally they stop breathing altogether, this may take a long time for some people and for others it might only take a few minutes.

Often the person's body will relax completely and they may look very peaceful.

## Afterwards

Following the death of a loved one you may feel very shocked even if you were well prepared. In most cases there is no need to do anything straight away and if you want to you can just sit with your relative or friend for a while.

When your loved one has died contact your GP in usual working hours or ring 111 out of hours.

As your loved ones death was not sudden and unexpected your GP will usually be able to give you a medical certificate and then you will be able to contact a funeral director.

## Changes to how a person looks

Often people become drowsy and begin to spend much of their time sleeping, and having very little interest in their surroundings. This is part of the natural process and may even be accompanied by feelings of tranquillity and peace. Eventually they are likely to become unconscious, for some this period will be short but for others it may last several days.

Their skin may become pale and moist and their hands and feet could feel cold. Parts of their bodies including hands and feet may become swollen, blue in colour, mottled or have an uneven colour, this is due to reduced circulation.

Putting extra covers or blankets might help to keep them more comfortable. It may also be helpful to put socks on their feet or gently massage their hands whilst you are holding them.

## Remaining at Home

As you loved one has decided they wanted to die at home the nurses, doctors and carers involved in their care will do all they can to try and support you in this.

Once home it is likely that your GP, a community matron from your GP surgery or a district nurse will speak to you about how you are managing.

A valid ReSPECT form (Recommended Summary Plan for Emergency Care and Treatment) that includes a Do Not Attempt Resuscitation decision will have been sent home from the hospital, make sure this is kept in a safe place which is easily assessable to health care staff.

You may have other documents in the home such as a recognising dying form, a statement of wishes or a lasting power of attorney, it might be helpful to keep all such documents together in one place.

It might also be useful to keep a list of who to call, this could be other family members, friends or other important contacts.

## Caring for someone at Home

If you need help in caring for your relative/friend then we will arrange for carers to visit regularly at home. The carers will provide personal care, attend to the persons comfort prepare meals and give oral medications, this care is often referred to as a care package and is provided by Continuing health care. The carers will usually be from a care agency.

Despite having this care in place family and friends may need to provide support in-between carer visits and it is likely that you will find this both physically tiring and emotionally difficult. You are likely to have good days and bad days but this does not mean you are not doing really well.

If you are struggling with the level of care needed don't be afraid to ask for help, there are support services available and it may be possible to increase the package of care. It is important you look after yourself and take time out if you need to.

## Physical and emotional changes

As people get closer to death, they become weaker and more drowsy and spend much of their time sleeping, Having less interest in their surroundings is part of this natural process which for most people is very peaceful.

### Eating and Drinking

It is normal for people to feel less like eating and drinking. At this time helping them to small amounts of soft diet and sips of fluid using a straw or a spoon may be helpful.

There will likely come a time when the person is unable to take food and drink and it can be difficult to accept that your relative has stopped eating and drinking, even though you know they are dying. If they start to cough or choke on food and fluids then stop giving them, the use of frequent mouth care at this time will help them feel more comfortable.

## **Breathing**

When the patient is getting closer to death their breathing pattern may change. Sometimes there are long gaps between breaths, or breathing may become fast and shallow.

Occasionally breathing may become noisy due to fluid collecting in the airways. Whilst this can be distressing to those at the bedside, this does not usually cause the person distress. This happens because they are comfortable with this fluid and do not feel the need to cough. Medication or a change of position may help.

## **Incontinence**

Often when people become weaker they may start to be incontinent and lose the control they have over their bladder and bowels. This may not always happen when the carers are present and while the carers will fit your loved one with pads it still may be something you will feel you need to deal with yourself.

## **Restlessness and Agitation**

Sometimes the patient will become restless, this is usually caused by chemical changes in the body, which affect the brain. Tell your district nurse or palliative care nurse if this is happening as medications may be useful in reducing the distress caused.

As people reach the end of their life, they may become confused and sometimes they will not recognise you, they may hallucinate and see things or people that aren't there. Quiet reassurance and words of comfort may help to calm them, remind them you are there and keep noise to a minimum. You might want to read to them or play them music they like to hear.

Physical problems such as constipation or being unable to pass urine may cause confusion and agitation. Talk to the district nurse/community palliative care nurse or carer who are visiting if you are concerned.

Sometimes restlessness is due to emotional distress and in such cases it may be helpful to talk to a trusted nurse or doctor,

## **Changes to medications**

Before discharge from the hospital the doctors will assess which medications remain helpful. Plus ensure that they are given in a way that makes them easy to administer, such as by an injection.

Also a range of "Just in case" injection medications will be prescribed and sent home, these can be used to by the district nurse to help control troublesome symptoms such as pain, sickness and agitation should they occur. Make sure these medications are kept in a safe place which is easily assessable to the district nurse.

Sometimes a device called a syringe driver is used to help control symptoms that persist. If you are contacting the district nurse frequently to administer medication then it's likely that medications will need to be increased or changed.

The district nurses can be contacted and asked to come as soon as possible to give injectable medications for symptom relief such as pain. To do this ring your GP surgery in working hours and 111 out of hours, mention to them that you need a district nurse visit to give "Just in case" medications.

## **Pain**

People in the last days of life may not be able to tell you if they are in pain. Common signs to look out for are grimacing (screwing up their face) moving as if they are distressed, and sweating. If any of these occur or you are worried your relative or friend may be in pain you will have oral medication in the house that you can give (if they are able to take it).

## **Religious and Spiritual needs**

There may be particular practices or prayers that your relative may have wanted. It's important to do whatever you feel is right. This may include asking a spiritual advisor to attend.

Though unconscious they may still be aware of your presence, your voice and your touch.