NHS
The Clatterbridge
Cancer Centre
NHS Foundation Trust

The plan of care in the last days or hours of life

Rehabilitation and Support

A guide for patients and carers

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The team looking after your relative or friend believe that there has been further change in their condition. Despite the best efforts of doctors and nurses, sadly, your relative or friend is dying, and is in the last days or even hours of life. A plan of care for them needs to be put in place.

The dying process is unique to each person and this plan of care will be tailored to your relative or friend's individual needs.

You and your relative or friend will be involved in all discussions regarding the plan of care. Both of you should fully understand the reasons why recommendations are being made. Please ask any questions if you are unsure. If your relative or friend's condition seems to 'pick up a bit', the plan of care for the dying will be reviewed and changed accordingly. You will both be told of any further changes to the plan. If after discussions with the senior doctors and nurses caring for your relative or friend, you do not accept or agree with any decisions made, you may want to ask for a second opinion.

If your relative or friend has previously told us about their wishes and preferences regarding their care at the end of life, we will aim to respect these as much as possible. If you are aware of wishes or advance care plans that belong to your relative or friend these may help us to provide the very best care for them if you tell us about them.

Medication / treatment

As part of the plan of care, medication will be reviewed. Medicines for symptom control will only be given when needed, following an assessment, at the right time and just the right dose to help the symptom. Any drugs that are not helpful may be stopped. New medication(s) will be prescribed quickly if symptoms occur.

We will make every effort to manage any symptom your loved one experiences as they near the end of their lives but there are some that we look out for more than others. Different symptoms are managed in different ways:

- **Pain.** It is not common to get more pain as someone dies but it if they do we often use morphine-based medications to ensure their comfort. More often, we need to use injectable morphine based medications to replace pain killers that the person was previously taking by mouth. As people often have increasing difficulty swallowing their medicines as they get weaker, we often use a special pump called a Syringe Driver to give medications under the skin so a person does not have to rely on their ability to swallow in order to get the medication they need to manage their symptoms.
- **Breathlessness.** Occasionally people do experience breathlessness towards the end of life - this often reflects the overall weakness their body is experiencing. In these situations, morphine-based medicines are also useful as they minimise the sensation of breathlessness for the person.

- **Agitation.** Some people experience a feeling of restlessness or agitation towards the end of life. There are different medications used to manage this and they aim to make the person feel calm rather than sleepy but often sleepiness is a side effect. This will always be discussed with you and your loved one before these medications are used.
- **Nausea.** Sometimes people suffer nausea as they approach the end of their lives. In this situation, anti-sickness medications are given in order to remove that sensation but they often need to be given using a syringe driver in order to make sure the act of swallowing the medicine doesn't make the sickness worse.
- **Respiratory tract secretions.** As people get weaker towards the end of life, occasionally their breathing will sound 'rattly'. This happens when secretions build up at the back of the throat and upper airway which the person is too weak to cough up or swallow down. Often the person is unaware of the secretions (they are often asleep when these occur) but it is difficult for family and friends to listen to. We do try some medications to dry up the secretions if they occur but sometimes they do not go away completely- we do however continue to ensure that the person is not distressed by them.

It may not be appropriate to continue some tests at this time; these may include blood tests or blood pressure and temperature monitoring.

The staff should talk to you about maintaining your relative's or friend's comfort. This should include discussion regarding position in bed, use of a special mattress and regular mouth care. You may want to be involved in elements of care but this is entirely up to you.

Diminished need for food and drink

Your relative or friend will be supported to take food and fluids by mouth for as long as they can possibly manage.

As weakness develops, the effort of eating and drinking may simply become too much. Help with feeding might be appreciated.

If your loved one stops being able to eat and drink and feels no desire for food and fluid, it is important you do not try to force them as you may run the risk of causing a choking episode.

When someone stops eating and drinking it can be hard to accept, even when you know they are dying. It is a physical sign that they are not going to get better. Your relative or friend may neither want nor need food and/or drink. Decisions about the use of artificial fluids (through a drip) will be made in the best interests of your relative or friend. You will likely be involved in the discussion around what is the right thing for that person which will help the doctors to make their decisions (if your relative or friend gives their permission). Any decisions around the use of artificial fluids are reviewed every day depending on how the person is so you can expect a regular update about what is happening with fluids for your relative or friend.

Religious / spiritual needs

Our plan of care includes the wishes of you and your relative or friend as regards religious or spiritual needs, and what is important to you at the end of life. Staff will ask you both about your wishes and take into account any previously recorded information.

You may be asked if you or your relative or friend have a religious tradition or belief and you may want to consider specific support from a chaplain / religious advisor, regarding special needs in the days or hours before death, or at the time of death or after death.

Not everyone who dies has a formal religious tradition. The staff should explore any other values, beliefs, wishes or desires that you or your relative or friend may have.

Practical matters

You should be given information with regards to such things as visiting times, car parking, beverage facilities, chapel or Quiet Room, and other services available.

Information / communication

As well as giving information to you about the plan of care, the staff will check that you fully understand the plan. Please do not hesitate to speak with the doctors or nurses, regarding any worries or concerns that you may have with the plan of care.

'Coping with Dying' leaflet is available if you want more information on what to expect at this time in relation to diminished need for food and drink, changes in breathing and withdrawing from the world.

Please be reassured that the team looking after your relative or friend will make regular assessments of their condition and will keep you informed of any changes.

The Nurses, Doctors and other staff are here to help you to work through your worries and how you are feeling and to offer you care and support at this sad and challenging time.

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How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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