End Of Life

in Intensive Care

People who are in Intensive Care Unit (ICU) are very ill. Even though they are having intensive care treatment, it's possible that they might not live.

This information sheet is for the family, a partner or friends of someone in an Intensive Care Unit (also known as a Critical Care Unit). It explains what happens when someone might be at the end of life in an ICU, what to expect and how to support yourself and the patient

ICUsteps
icusteps.org

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Introduction

This information explains what may happen at the end of someone's life in an intensive care unit. It explains about the care and support given, including what people may experience in the last hours or days of their life. We hope this may help to prepare you if you have a family member, partner or a friend who is very ill in intensive care and if it is possible that the person may not live.

We have used the words Intensive Care or ICU (Intensive Care Unit) in this information, but some hospitals call this the Critical Care Unit. We have also called the healthcare professionals looking after the patient their 'care team' and 'ICU team'.

You do not need to read all this information. You can read bits of it, when and if you want to. The contents list can help you to read the parts that are useful to you. The nurses and doctors in the ICU will also do their best to support you and answer any questions you may have.

Intensive care treatment can support people when they are very ill, with medicines and machines (for example, machines which breathe for people). Sometimes, people are too ill to live. If they are not getting better and it is not in their best interests to continue treatment, their care team will talk to you about what will happen next and explain how the person will be cared for at the end of their life.

One of the very hard things about critical illness is that it is often not clear who may get better and who will die. Sometimes all the ICU team can do is see how a person responds to their treatment.

> *"It can be a very frightening time when there are no clear answers"*

This can be a very difficult time for family, partners and friends who are often desperate to know what is going to happen. It means they don't know if they are getting ready for the person to die or whether to prepare for their recovery. It can feel like a rollercoaster, where there can be better news and then bad news, and sometimes this changes hour by hour, as a person's condition changes. You may think that the doctors must know if your relative, partner or friend is going to live, but it is not always that clear and critical illness means things can change very quickly. It can feel a very frightening time when there are no clear answers.

End of life in ICU

People who are at the end of their life in ICU will be cared for and looked after right to the end of their life with the same dignity and respect as if they were to live.

This section gives more information about things you might want to know about end of life in an ICU.

> *"People who are at the end of their life in ICU will be cared for and looked after right to the end of their life with the same dignity and respect as if they were to live"*

How does the ICU team know if a person is at the end of their life in ICU?

ICU treatment uses machines and medicine to help people while they are very ill. This is sometimes called 'life support' or 'life sustaining treatment'. The patient may be only partly awake (called 'semi-conscious') or they may have been given strong drugs to keep them asleep (called an 'induced coma'). This means that it may not be clear to you that they are getting more ill, and that ICU treatment isn't helping them to get better. The ICU team will be looking closely at how the patient is, and checking their monitors (for example, the machines to show their heart rate). They will look at their blood test results and how much help they need for their breathing and blood pressure. All this information helps them to see if the person is getting better, staying the same or if they are getting more ill and they might die.

If a person is becoming more ill, even with ICU treatment and machine support, then it may not be in their best interests to carry on with the treatment. ICU treatment can be very upsetting for patients and sometimes it can cause long-term harm to their body which will not get better. The patient may be very confused, restless or upset, and they may not understand where they are. ICU treatments can be very uncomfortable. It is not in a person's best interest to carry on with this intensive treatment if it will not help them to live, or if their quality of life will not be one that they would like.

> *"Identifying that someone is at the end of life means they will be given the right care to help them during this time"*

If their ICU team decide that it is not in the patient's best interest to have intensive care treatment, or they are dying, this does not mean that they will not be cared for. Identifying that someone is at the end of life means they will be given the right care to help them during this time.

If the patient is too ill to say what they want, how is it decided what treatment is in their best interests?

Making the best decisions for a person who is too ill to make their own decisions is called a 'Best Interests' process. It needs teamwork between the professionals and the people who know the person who is ill (such as their partner or family members). What treatments the person might be able to have will be decided by the ICU team. Then it needs to be decided if it is in the person's best interests to have this treatment. The care team will want to try to involve those close to the patient in these discussions.

To help decide what is in a patient's best interests, information is needed. The ICU team will speak to other doctors who know about their illness or condition (in their own team or other doctors in the hospital) and also to people who know the patient well. They will look at the patient's illness and the possible treatments, and balance what the treatment might do for the person against what suffering or harm it might cause them.

As part of this best interest discussion, they may ask you what the person thought about illness and treatment, and what they may have said to you before they were ill. This helps the doctor understand what the patient might have wished to happen. These wishes may be different from the wishes of their family, partner or friends. When having this conversation, you are not being asked to decide what treatment the person will have, but just if they had said anything to you about serious illness and treatment. It can sometimes be hard to say what that person would have wanted if they hadn't spoken about it with you. It's ok to say you don't know.

The doctor will also ask you if the person had already filled in a form to say if they would not want cardiopulmonary resuscitation (called C.P.R., which tries to restart someone's heart if it has stopped) or to not have some life-sustaining treatments (such as having a machine to breathe for them) or if they may have spoken to doctors, family or friends about what they would want to happen (called an Advance Statement or Advance Care planning).

If the patient has previously chosen someone to speak on their behalf and given them legal Powers of Attorney, then that person (or group of people) can turn down the treatments offered by the ICU team, just as a patient might. The decision-makers are either the people with Powers of Attorney or, if there is no-one with

What is Power of Attorney?

Power of Attorney is a legal document which states that a person has chosen someone or a group of people to work together to speak on their behalf if they are not able to. This is called a Lasting Power of Attorney for Health and Welfare (England and Wales) or Power of Attorney (Scotland and Northern Ireland). If their Attorney(s) have permission to be involved in decisions about life-sustaining treatments, then they should be part of this best interests decision-making process and be asked what the person would like to happen. They also have the right to refuse particular treatments on the person's behalf. They cannot request or demand particular treatments for the person though.

Without a legal Power of Attorney, nobody has a right to consent for treatment on behalf of an adult (someone aged over sixteen years old), not even their partner, family member or their parents.

Powers of Attorney, the most senior doctor in charge. The decision makers cannot ask for a particular treatment for the patient though, they can only discuss it to say yes or no to the treatment being offered by the ICU team.

If Best Interests Decisions need to be made, the care team will talk you through the whole process of making decisions and about how the decision will be made. The care team will involve those close to the patient to make sure an appropriate decision can be made about the person's best interests. It may take several conversations to arrive at the best answer.

There is information on p.22 if you are worried that the treatment plan for the person is not right.

Where a person is looked after at the end of their life

Once a person is known to be dying, or if it is not in their best interests to carry on with intensive care treatment, their medical team will think about where they can be best cared for. You may be asked where the person might want to be when they die. If it is decided that the person no longer needs intensive care treatment, they may be moved to a general ward.

Sometimes it may be possible that the person could go home or to a hospice. This will depend on how ill a person is, what their care needs are, and if there is time to arrange for them to leave hospital.

The ICU team will talk to you about where the person will be cared for. The palliative and supportive care team (the team that advise about care for people's symptoms) may be invited to give their advice, too.

What happens in 'ordinary' dying?

When people are dying, perhaps at home or in a hospital ward, but not in an intensive care unit, there are common things that happen. Dying is a process with stages that are often similar between people at the end of life. There can still be some uncertainty in the last stages of life, such as exactly when a person might die, but it is much easier to know when people are nearing the end of their life if they are not having intensive care treatment.

A dying person may:

- become very tired and sleep a lot
- find it difficult to swallow or to take medicines by mouth
- not be interested in eating and may stop eating
- not want to drink much, and then may stop drinking
- feel hot or cold to touch
- be confused or not know where they are
- feel emotional
- not want to talk or see people
- lose interest in what is happening around them
- not be strong enough to leave their bed to go to the toilet. They might need to wear changeable pads instead
- sometimes be upset or become restless
- become unconscious (seem asleep but not able easily to wake up).

It is common that breathing patterns will change for people who are dying. This includes:

- different breathing patterns, perhaps fast for a while, then slower, then fast again, or moving between deep breathing and more shallow breaths. Sometimes there can be gaps in their breathing.
- noisy breathing. You may have heard this called a ‘death rattle’. Medicine can be used to stop this if it seems to be bothering the person, but many patients do not seem to find it upsetting. It can be a sign that they’re relaxed and comfortable and not upset by the mucus in the back of their throat (as they are not coughing or gagging on it).

What happens when a person dies in the ICU?

When someone dies in the ICU, some of the same things can happen as in ordinary dying, but there will be differences when machines and ICU medicines are being used.

The care team will try to help dying to be as comfortable for them as possible. This will mean that some of their treatments will be changed to comfort treatment, rather than life-sustaining treatment. The ICU team will talk to you about this care and what will happen about breathing support and other machines and medicines which are no longer useful to the patient.

If their team decide that some of the machines and drugs that are no longer useful to the patient (like certain medicines that keep the blood pumping around the body), they will plan to take them away. They will look to see how the person is and what other support they might need instead, so they will remain comfortable. The nurses will be looking after them with as much care as they did when this was life sustaining treatment.

> “The care team will try to help dying to be as comfortable for them as possible”

Nurses may take out drips and lines if they are not needed by the patient. Once a person is at the end of life, it will not be as important to check their blood pressure, heart rate and oxygen levels so often. This may feel worrying to family, partners or friends who have been with the patient in the ICU and who saw these things so closely checked before, but the nurses will be concentrating on making the person as comfortable as they can be and looking for and managing any symptoms that the person may have which might be making them uncomfortable.

What changes might there be in a person who is at the end of their life in an ICU?

You may see changes in how the person looks or how they might be as they become nearer to the end of their life.

There can be medicines to help with some of these changes if the person seems uncomfortable. However, giving too many medicines may not help the person because they might cause other side effects. For example, medicine for pain might cause sickness or stomach pain, so the care team will carefully look at what medicines they have to make sure that the person is as comfortable as possible. Here are some of the things that people can experience at the end of their life in the ICU:

Changes in breathing

Changes in breathing are a natural part of dying. Breathing can be slower, faster, noisy or have gaps between the breaths. When a person is having breathing support during the end of their life, these natural changes may be less obvious. If they are on a ventilator (a machines which is breathing for a person), you may not notice any changes at all.

When ventilators are not needed at the end of life, the care team will plan carefully about how to stop this treatment. For some people, they may not be able to breathe on their own without the machine and so they may die very quickly once ventilation is stopped. Some people might be able to breathe on their own when the ventilator is first taken away, and then their breathing will slow and stop. Breathing can be noisy, and medicine can be used to make people more comfortable if that is needed.

Breathlessness

Some people may be breathless if they are awake and aware, and this might make them feel anxious or upset. Nurses might try simple things to help them, such as holding a hand-held fan to their face, as the feeling of air on their face might help with their feeling of breathlessness. Sometimes medicines can be given to help breathlessness if the person seems upset by it.

Mucus (phlegm)

When people are in ICU, it is common for mucus to build up in their lungs because they are not able to cough it up or swallow it. If the person has a tube in their throat to help their breathing (called a tracheostomy), nurses may take away some mucus by using a suction tube put down their tracheostomy. This suction isn’t comfortable, and it can make the person cough or retch when it is being done.

Once treatment is changed to provide comfort care because the person is dying, the ICU team may feel it is more comfortable for the patient not to have this suction. If the mucus is upsetting the patient, the staff may give medicine to help with this mucus or see if there are other ways to make them feel more comfortable such as changing the person's position in the bed.

Skin

The person's skin may look different when some of the machines and medicines are stopped. This is because there will be changes in how quickly blood is pumped around their body by their heart. Their skin may become more pale, dark, blotchy and feel cold to touch (especially around their hands).

Nurses will check the patient's skin often to avoid it being hurt by pressure (which are called 'pressure sores') and they will change the person's position in bed to help with this, if it is safe to do so. They will also wash the person and use creams, or a special mattress, to help stop pressure sores.

Pain

Nurses will try to keep the person who is dying out of pain and as comfortable as possible. They will check often for any signs of distress or pain. If the patient seems to be in pain, medicine can be given if it will help them. It may be given in a drip, or through a tiny needle placed under the skin. If you feel your relative, partner or friend is in pain, do let their care team know.

> *"Nurses will try to keep the person who is dying out of pain and as comfortable as possible"*

Sometimes people who are dying can seem to be in pain because they are uncomfortable or restless, but changing their position in their bed can help to settle them.

Seeming upset

Becoming restless, upset and confused is often part of the natural dying process. If the person seems to be uncomfortable in this way, the nurses and doctors will check for any other reason for this, such as pain. They will see if there is medicine that may help them.

Some of the drugs that can help with these symptoms can mean that a person is less aware and becomes more sleepy. The person may be more awake on lower doses of medicine, (and it may feel important for them and for you to be able to speak or communicate as they are more awake) but they may be less comfortable. With higher doses, they may be more comfortable, but also more sleepy. Their care team will work to get the right balance between comfort and awareness.

Delirium

Delirium is a name for acute confusion. It is sometimes described as like being in a vivid dream or a nightmare, but it can feel very real. Someone with delirium may be hallucinating, which means they can be seeing, hearing, or feeling things that don't exist outside their mind. They can imagine that different things are happening to them, and this can be very frightening. It is common for people in ICU to have delirium, including those who are the end of life.

There are ways you can try to help someone with delirium, such as:

- holding their hand and reassuring them
- telling them often that they are in hospital, and they are safe
- talking with them. Use a calm voice which can help to make them feel safer
- If the patient is sedated, and you are not sure what to talk about, try reading a favourite book or a newspaper to them. They may find it comforting to hear your voice. Choose what you are reading carefully to make sure that it doesn't upset them more.

You can find out more about delirium here:
https://icusteps.org/assets/files/information-sheets/delirium.pdf

Sickness

There can be many reasons why a person is being sick (vomiting) or feels sick (nausea) at the end of their life. It may be due to their illness or the side effect of medicines that they are taking. There are medicines which might help with this sickness if it is upsetting them.

Emptying bowels (to poo)

As the person becomes more ill, they will not be able to get out of bed to use a toilet. They may not be able to control when they have a poo, or they may be uncomfortable because they are constipated (being unable to poo). People can also sometimes also have diarrhoea (having poo that is watery) when in ICU and they will need medicine to help with this. Their care team will work out how to best to help them if they are uncomfortable.

Emptying bladder (to wee)

Most people in ICU have a tube (called a catheter) into their bladder to drain their urine (wee). The catheter is usually left in place to make sure the person is comfortable and not feel as if they need to wee.

Eating and drinking

Many people in ICU are not well enough to eat and drink. They may be fed by a feeding tube which goes from their mouth or nose into their stomach, or they be fed by a drip. This is a tube which goes into their arm or neck and is called intravenous (IV) fluids. This is called clinically assisted nutrition and hydration (CANH).

A natural part of dying is that people become less hungry and less thirsty. This is sometimes difficult to know if a person is receiving CANH (because they are being fed without needing to eat, and most people in ICU have IV fluids, which means they do not need to drink). If the person is comfortable, it may be ok to carry on with the CANH. However, if the person is uncomfortable, for example it is stretching their stomach, their care team may feel it is in the person's best interests to stop it. For some people this can help them feel sleepy and less anxious, which is a normal part of dying.

There is helpful information about CANH from the British Medical Association here **https://www.bma.org.uk/media/1169/bma-leaflet-canh-a-guide-for-family-and-friends.pdf**. Families can feel upset about this aspect of dying and end of life care, so do talk to the ICU team if you have any worries.

Feeling hungry

At the end of life, many people are sleepy or have been given strong medicine (this is called being sedated), and so will not feel hunger, but some people might feel upset from feeling hungry. Their care team will be looking out for any sign that the person is not comfortable and will see how this can be helped.

Feeling thirsty and mouthcare

It is common for people who are dying to feel thirsty or to have a dry mouth or tongue. Their breath may also smell. Nurses will give them mouth care to make them more comfortable, such as a wet swab which can be used to add a bit of moisture in their mouth and lips. They might also use ice (if allowed and available), sprays, lip moisturisers and gentle tooth brushing. You can ask the nurses if you would like to do this for the patient, and if it's ok to do it, they will show you how.

What else can be important to people at the end of their life?

Communication (talking with) your relative, partner or friend
It is likely that the person who is dying will seem to be asleep, either because they are naturally sleepy, they are unconscious or have been given strong medicine (called being in an induced coma or being sedated). If you feel able to, do talk with them, even if they do not seem to be awake. They may still be able to hear you and hearing your voice could be very reassuring to them. They may be confused about where they are or what is happening, so it's helpful to tell them they are in hospital and that you are with them.

> "It might be possible to make a more peaceful space around their bed for the person who is dying"

It can feel difficult to keep up a one-sided conversation, so you could read a book or a newspaper to them (though choose something calming that will not confuse or upset them). They may find it comforting to hear music played which they like. Music may help them if they seem upset or restless.

If there are things you want to say to the patient, but you are finding it difficult as they are not able to talk back to you, you might be able to talk with someone in the same room so that the patient can hear, perhaps to a nurse if they have time or to someone also visiting the patient.

If the person is more awake, they may be able to communicate with you. They may not be able to talk if they have a tracheostomy or a breathing mask on, but nurses will see if there is a way they can communicate with you, such as by writing things down or pointing to a letter or picture board. They are likely to be confused or delirious, so do not worry if they do not make sense. Let them know they are in hospital, and they are being looked after. Speak calmly and gently as it could comfort them if they see that you are calm.

Area around their ICU bed

It might be possible to make a more peaceful space around their bed for the person who is dying. For example, machines with monitor screens can be turned away (and alarm volumes turned down).

Sometimes it may be possible for ICU teams to take patients outside to get some fresh air, if it is safe to do so, but not all units are able to offer this.

Other things which might comfort the person who is dying:

- pet therapy (where specially trained animals are brought into the ICU)
- softer lighting (like lamps)
- patients' own belongings, like pillowcases/blankets, but ask the care team first as this may not be possible because of infection prevention
- familiar music
- familiar smells which they like (such as their perfume, after shave or an essential oil)
- photographs of family and friends or of places which are special to the person.

Religious and spiritual needs

If religion or spirituality is important to the person, speak to their care team to let them know. There may be ways to support this at the end of life in ICU.
For example:

- religious icons or pictures might be able to be brought in
- family or friends could read prayers or religious readings to the person.

It may be that a religious leader or member of their community can come to visit the patient if it would be comforting for them. This could be arranged by the hospital Chaplains. The hospital Chaplains can also give spiritual and non-religious support to the person and their family or friends. You can ask the care team about how to contact the Chaplain.

Cultural needs

If there are cultural needs or rituals that are important for the person to have at the end of their life, speak to the nurses to let them know. This could include things like meditation or reading poems. They will try to help with these if they can, but it will depend on what is possible in the ICU.

There may also be cultural customs for looking after the person's body after they have died. Let their care team know to see if these are possible.

What else might it be helpful to know about end of life in ICU?

Visiting

Sometimes friends, a partner or relatives prefer to remember the person as they were when they were well, and do not want to visit them in hospital. They might find it very upsetting to visit the patient in ICU and they prefer to be updated by family members instead. This is ok. Instead, they may prefer to say goodbye by phone, or make a voice message to be played to the patient or send cards or pictures to them.

> "Even if the person who is dying is not able to speak, hearing a voice of someone close to them could be comforting"

When visiting is not possible

Sometimes ICUs are not able to have many visitors due to an infection outbreak or if your family member has a serious infectious disease. It can be very hard for friends, partner and family not to be able to be with the person at the end of their life. Talk to their care team in case visiting is possible. If this is not possible, it is best to let the ICU team know one person to call, and nurses will keep them updated and let them know how the person is. This person can then tell other friends and family what is happening.

If someone is not able to visit, but who is very important to the person who is dying, it may be possible for them to be on a video or phone call to the patient. Even if the person who is dying is not able to speak, hearing a voice of someone close to them could be comforting.

If you do have a video call, it is important that you have some preparation for what you might see. See if you can speak to a nurse to ask them what you might see before you have the video call. The person is likely to look different from when you last saw them, they may have tubes attached to them, and they may be confused or agitated. Their care team are doing all they can to keep them comfortable, but it can be upsetting to see them in this way.

If it is not possible to visit, it might be possible to record a voice message for them, or have a card or letter read to the person by a nurse.

Children

It can be difficult to know what to say to children about what is happening when someone is very ill in intensive care, especially when it is not clear if the person will live. Generally, it is best to be as honest as possible with children, explained in a way suitable for their age. This may feel hard to do but it can help children to know the truth rather than having it hidden from them. You could ask their teacher at school or a nurse at the ICU if they have any advice about how to talk to the child about what is happening. It is important to use plain language, such as dying or death, and not to use words that might confuse the child such as ‘asleep’ if the person has died. Reassure them that the patient is being looked after and cared for by the ICU team.

> *“Reassure them that the patient is being looked after and cared for by the ICU team”*

If the person who is dying has children, you may need to think about whether the child or young person should visit the unit. You should check with the ICU staff before bringing children to the unit and talk to the child or young person about it. If you decide it could be helpful for the child to visit, ask the child or young person if they would like to go. Think carefully about who will support them during the visit. They will need an adult to be with them who can be calm and put the child’s needs first. Talk with the staff at the ICU about the visit so they can ensure they are prepared for the visit and ask them, if possible, to reduce noises and other sights or smells that might be upsetting. Prepare the child for what they might see, including the machines, how the patient might look, that the patient will not be able to talk to them etc. Let them know they can leave when they want to, even if the visit is only a few minutes long. This preparation is also very important if the child or young person is visiting virtually by screen.

The child or young person may have questions afterwards, and the doctors and nurses might be able to help with answering some of them. Make sure the child or young person is supported afterwards, as it is likely to have been upsetting for them.

If the child or young person does not want to visit, they may like to make a voice message to send to the person, or a card or letter to be read to them. It might be comforting for the child or young person to feel a connection to the person in ICU, so you can ask them if they would like to send a message.

ICUsteps has information for children who are visiting an ICU, or who have a relative in ICU, including a parent and carer information sheet here; **https://icusteps.org/information/for-children**

There are also other resources for talking to children or young people when someone close to them is dying and charities who provide support for them after the person has died (see 'More Information' on p.29).

Medicine given to help the person who is dying be more comfortable

Where they can, the care team will give medicine to help the person dying be more comfortable. They will look at whether symptoms (such as noisy breathing) are upsetting the person, to see if medicine is needed. They will look to see how much medicine the person can have to keep them as comfortable as possible, without giving them too many unpleasant side effects, which might also upset them.

When a person will die

Although the person is dying, it can be very hard to know when they will die. Sometimes it can happen quickly, but sometimes it can take longer. The staff might be able to give you a rough idea, but it will be difficult for them to be able to tell you exactly when it will happen. This might feel frustrating when you want to know what is happening or if you are trying to arrange for other people to visit.

This can also make it hard to know when to leave the person so you can rest, eat and drink, but it is important that you look after yourself too. The nurses will call you if there is any change in how the patient is.

When a patient is connected to a lot of machines, and these are no longer used, they are much more likely to die very quickly. This could be as quickly as within minutes or a few hours. The ICU team can tell you when these machines are planned to be stopped being used.

Organ donation

If the decision has been made that life sustaining treatment is not in the person's best interest, the patient may be able to donate organs or tissues to help other people who need them (this is called transplantation). A specialist nurse in organ donation may speak to you to give you some information and discuss the option of donation. There is information about organ donation for families here: **https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/get-the-facts/**

DNACPR and decisions not to have life-sustaining treatments or to stop these treatments

When someone is very ill, some treatments might hurt the person's body, some will not work and will be upsetting for them, and so having them is not in their best interests.

> "A DNACPR decision is only about CPR. It does not stop any other treatments being considered or given to the person"

CPR (cardiopulmonary resuscitation) is a treatment to try to restart the heart when it suddenly stops beating. Medical staff giving CPR use both hands to push down hard on the chest. They might also use an electric shock to the chest to try and get the person's heart beating again. The heart might start beating again when a healthy person has a heart attack, but it may not work when the heart stops while someone is already ill with a major illness or injury. CPR does not always restart the heart and even if the heart is restarted, there can be some brain damage from the heart stopping and lack of oxygen to the brain. If CPR is used as a treatment on a dying person, it is likely to cause their body and mind harm, and it is unlikely to stop death from happening.

The person who is in ICU may already have decided that they do not want CPR and they have a DNACPR (Do Not Attempt cardiopulmonary resuscitation) statement. Or they may have said or written what other treatments they would not want to have, and filled out a form for this, such as the RESPECT form. Find out more about Advance Care Planning and discussing CPR at http://talkcpr.wales.

When a person is in ICU, the ICU team will see if they need a DNACPR (Do Not Attempt CPR) statement if they do not already have one. This means that CPR will not be given if their heart stops. This might be because the person is already so ill that they are dying, or if the person is known to have health problems that would stop CPR from working (such as brittle bones, some chest conditions, or other medical issues). DNACPR decisions are there to protect a dying person from this upsetting experience if it will not help them.

A DNACPR decision is only about CPR. It does not stop any other treatments being considered or given to the person.

CPR is only one of the treatments that may not help someone when they are dying. The care team might talk to you about other treatment decisions, including what treatment is not wanted by the person. This might include treatments such as having a tube in the throat for air (called intubation) or breathing with a machine (a ventilator). Each treatment will be looked at to see if it might help the person, if it might harm them or if it is no longer of use to the person who is dying.

Social media

Families may want to post messages or photographs on social media for friends and family that can't visit. It is important that this is done only with the permission of the person who is dying as they might not want to have pictures or information about them shared. If the person who is ill is not able to give consent, then you must not post pictures of them.

What family, partner and friends can do to support the person who is dying

Speak to the person's care team to see if there are ways you can support the person who is dying. You might be able to:

- gently reassure the person by talking to them, reading to them or just by being with them
- hold their hand
- give mouth/eye care and help with hygiene care, like hair washing and brushing
- give a hand or a foot massage
- video or phone call so they can hear the voice of people important to them.

If you do try some of these, see how the person responds and stop if it does not seem to comfort them.

Here are some things to think about:

- Do they have a religious belief that is important to them?
- Do they have cultural needs, or specific beliefs or things they would want to happen before or after their death?
- What might be comforting for them to have with them, such as photos?
- Are there any changes to the bed space that could be made, such as lower lighting, or music which they like, if possible?

If you do not know if the person may die or if they may live, you might want to think about these things, just in case they are needed.

How family, partner and friends can look after themselves during this time

Having someone very ill in the ICU is a difficult and upsetting time. It is important that you take care of yourself too. This includes having time to rest, eat and drink, though it can feel hard to leave the person to do these things.

Other things that may help you are:

- asking friends and family to support you. You can ask for specific things, such as lifts, food to be cooked, jobs to be done to help you, or just to be there if you ask for help.
- speaking to the hospital chaplain who will talk with you and listen to you, even if you do not want religious support.

- speaking with someone from a religious community, such as an Imam or a Vicar. They might be able to provide non-religious (pastoral) support as well.
- asking a friend or family member to send emails or messages to let other family and friends know what is happening, so you can focus on being with the person who is dying and taking care of yourself.
- speaking with the nurses and doctors if there are things you want to know.

If you are worried that the treatment plan for the person is not right

If the person is too ill to say what treatment they want to have, then the law says that medical decisions about their care have to be made by the senior doctor in charge, or by a person or people who have been given Power of Attorney by the patient, using a best interests process. See p.5 for more information about this.

> *"Having someone very ill in the ICU is a difficult and upsetting time"*

After a best interests treatment plan has been decided, you or family members or friends may think that a different treatment plan will be better for the person. Sometimes, there may be disagreements between you and other family members and friends about what is best.

If someone does not agree with the treatment plan and care that a person is getting, it is important to talk with their care team to find out more. The ICU team will explain the reasons behind these decisions, and hopefully there will be understanding and agreement. If you are still worried, then you can ask to speak to the Matron or Clinical Director of the ICU. The hospital chaplain or Hospital Patient Advice Liaison Services (PALS) may also be able to help. You can ask for a second opinion by another doctor you know and trust or ask the ICU team to find one. It is best if any disagreements are resolved in the hospital if possible.

If you have spoken to the Matron or ICU Clinical Director and you are still concerned about the treatment plan for the patient, there are local mediators (including the hospital Clinical Ethics committee) or independent advisors which might be able to arrange for a second medical opinion. You can ask the hospital's

Patient Advice Liaison Services (PALS), who may have contact details for these mediators and advisors. In rare cases that families are still not able to agree about the treatment plan, there is the option to go to the Court of Protection; **https://www.gov.uk/courts-tribunals/court-of-protection**.

What happens after the person dies?

After a person dies, they are seen by a doctor to confirm that they have died. Nurses will make sure that your family member, partner or friend continues to be cared for. They will then be moved to the mortuary (the place in the hospital where people who have died are taken).

Ask the nurses if you would like to help with care after your family member, partner or friend has died, such as washing them. This may also be important for their religion or culture. You do not need to do this, as the nurses will do it for them, but you can ask to do it if you want to, and the nurses can help you.

If you would like a handprint, fingerprints or a lock of hair from the person who has died as a memento, please ask nurses if this is possible.

The person will be moved to the mortuary quite quickly after they have died, perhaps one or two hours, as people who have died need to be kept in a cool room. They will stay in the mortuary until you or a family member arranges for their body to be collected by a funeral undertaker.

If you are the person's next of kin (the person/people named on hospital admission to be informed and consulted about their condition), you can take their belongings home with you when you leave hospital, or the items will be kept for you to pick up at another time. Ask where you should go to collect their belongings, as it may not be the ICU or the ward where the person died.

If the person has had recent treatments, such as chemotherapy or an operation, or there are any questions about why they died, then their death may be looked at by the Coroner. This is a person legally appointed to examine causes and circumstances around certain deaths (such as those that happen following a recent operation). It is not unusual for this to happen. Bereavement Services in the hospital will contact you about this. If the Coroner does need to look at the person's death, you may need to wait to make funeral arrangements, but the Hospital's Bereavement Office will be able to tell you more about this.

You can contact the Bereavement Services in the hospital (or they may contact you once you have left the hospital) to make an appointment for you or a family member to collect the medical certificate of death. If the Coroner is looking at the person's death, then the medical certificate of death will not be ready until they have finished this process.

The Bereavement Services team will talk to you about the next steps, such as registering the death or choosing an undertaker and answer any questions you may have about what happens next. They will also let you know whether you need to come into hospital to collect the medical certificate of death or if it can be sent to you.

Will I have contact with the ICU after the person has died?
Sometimes the family of a person who died is contacted by a member of the ICU team at a later date. They may ask if you have any questions about what happened or to offer you support. They may be able to tell you more about why the person died if there are things that you don't understand or can't remember.

"The death of someone close to you can leave you with many feelings"

They will understand that this may be difficult for you to speak about, or that you may not want to talk about it at this time and you do not have to speak to them. Sometimes people have questions some time after someone died, as they begin to look back on or try to understand what happened. It can be very difficult to understand everything at the time, especially if the death happened quite quickly.

If you have questions but you haven't been contacted by the ICU team, you could contact the hospital's Bereavement Service or their Patient Advice and Liaison Service (PALS). You can also contact the ICU directly if you have been given information from the ICU to say you can contact someone there after the patient has died.

How you might feel after the person has died

The death of someone close to you can leave you with many feelings. You may experience a range of emotions such as devastation, anger, disbelief, numbness, tiredness, helplessness as well as deep sadness. These can take time to come out and you may find your emotions changing day to day, hour to hour. This grieving process takes time. There is no ‘right way’ or ‘wrong way’ to feel and everyone who is grieving alongside you may feel or act differently to you.

Grief

Grief is how we can feel when somebody close to us dies. We can experience grief in different ways and there is no ‘normal’ or ‘right’ way to grieve.

When death is unexpected, this can be especially upsetting as you haven’t had time to prepare for it. To begin with, you may feel numb. What happened may seem like a dream, or something that has not really happened, or you may be getting strong memories coming back to you (called ‘flashbacks’) of things that happened when the person was in ICU.

When someone has died in ICU, it can lead to strong and sometimes unexpected emotions, especially when the person’s death was unexpected. This is all part of the grieving process, and it’s important to find support to help you with how you feel, if you are finding it difficult. Grief can affect our body and mind in unexpected ways. You may find it difficult to sleep, have flashbacks to what happened in hospital, not feel like eating or you may want to drink more alcohol than usual. Do contact your GP if you need support or contact the Good Grief Trust to see what other support there is **https://www.thegoodgrieftrust.org**.

In time, you might find it helpful to find out more about what happened when the person was in ICU, if you feel you want to. You may have confused memories of that time or found it hard to take in information. It might be helpful to read through this information sheet again to help you understand more about what happened, if you want to.

Please see ‘useful contacts’ on p.29 for organisations that can offer support during this difficult time.

Questions you might have while someone is in ICU and afterwards

How might I feel while someone is in ICU?

This is a very difficult time for you and the person's friends and family. It might be that it was not expected that the person would be so ill. It may have happened very quickly, so you've had no time to prepare for this. It is very hard when there are not clear answers about how the person will respond to treatment and if they will live. You can feel desperate to know what is going to happen and want to have clear answers when there are not any. You might not be sure what is the best treatment plan, and the person is likely to be too ill to say what treatment they want to have.

> *"Ask for support from the people around you. Your needs are important too".*

You may not understand why the treatment is not working. You may struggle to believe the situation or feel angry with the care team for not being able to help the patient. You may not agree with the decision that it is not in the person's best interest to have more treatment. You might feel scared, or very sad. People all react differently. Staff understand that and will do their best to answer your questions. Ask for support from the people around you. Your needs are important too.

What happens if the person who is in ICU looks like they are getting better even though it seemed as if they were dying?

Sometimes a person may seem very ill and then they become a little better. Their care team will be closely checking to see how they are, and they will change the treatment plan as the person needs it. They will talk to you about any new care and treatment plans.

What would happen if the person who is dying becomes very ill and I'm not there?

If you are not in the ICU when your friend, family member or partner becomes very ill, and if you are the named person to call, their care team will try to call you to let you know. The nurses will be with the person who is dying, and they will comfort them. Unfortunately, sometimes people do become very ill very quickly and die, and it may not be possible for you to be there in time, but they will be cared for, and they will not be left alone.

Why am I being asked about research?

It is important that ICU teams know the best way to care for people who are being treated in ICU. Research is part of normal clinical treatment, so nearly all ICUs will be involved in research projects. You may be asked if the patient (if they are too ill to say), or you, might want to take part. The research nurse or team will explain what the research is and what is involved. You will have time to think about it before saying yes or no. What you decide will not affect how the person is looked after, and the ICU team will still act in the patient's best interest and give them the care they need. If you agree for the patient to take part, and then change your mind and decide that you don't want them to, you can let their team know. You can find out more about research in ICU here;
https://www.youtube.com/watch?v=6HOTEIv46ec

How long can I stay with someone in ICU once they have died?

You may stay with your friend, partner or family member for a short while, but they will need to be moved to the mortuary (the place in the hospital where people who are died are taken) quite quickly (usually one or two hours). The ICU staff will understand that this could feel difficult, especially if the person died quickly or unexpectedly, but their body will need to be moved to a cool room. It may be possible to arrange to see the person's body, either at the mortuary or the funeral undertakers. Families can speak with the ICU team, the hospital's bereavement office or the undertaker to see if this is possible.

What is the difference between a medical certificate of death and a death certificate?

When someone dies, a doctor provides a medical certificate of death. This certificate is then taken by the person's next of kin or family member to the Registry Office (the place where deaths are officially recorded) who will then give a death certificate. This death certificate is often needed by banks, insurance companies and other companies for their records. The Registry Office will explain this in more detail to the person who registers the death.

Conclusion

Being with a person who is ill enough to need ICU treatment can be very worrying and difficult. If the person becomes too ill to live, then there may be lots of medical information to talk about and understand. You may take part in conversations about the person's wishes for their care and treatment. ICU staff are there to look after each patient, but they are there for you, too. They understand that this is a difficult time for you, and they will do their best to make sure you have information about what is happening to the person who is dying.

> *"The care teams will try to make sure that their dying is as comfortable, and with as much dignity, as possible".*

When someone is dying in hospital, their care teams will try to make sure that their dying is as comfortable, and with as much dignity, as possible. This information leaflet has been written by a team, including a patient and relative representative, a palliative care doctor and ICU healthcare professionals. We hope it will provide some comfort by helping you to understand more about what is happening, and to think about the things that matter most to the person who is dying.

More information

Here are some contacts that may be helpful to you during this time.

- Some hospitals offer the opportunity to speak to a member of the intensive care team at a later time, and you can ask if this is possible.
- Speak with the hospital chaplain. The chaplain is there to provide a listening ear, emotional support and spiritual support to patients, relatives and friends, including bereaved family members. People don't need to have a religious faith to use this service.
- To find out more about CPR, visit **http://talkcpr.wales** website. Their goal is to encourage conversation about CardioPulmonary Resuscitation (CPR) for people affected by life-limiting and palliative illnesses.
- Find out more about organ donation at **https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/get-the-facts/**
- The Good Grief Trust website has useful resources, and signposts bereavement support available across the UK as well as services local to you. **https://www.thegoodgrieftrust.org**
- CRUSE Bereavement Care offers information and support. Telephone no: 0844 477 9400. **https://www.cruse.org.uk**
- Marie Curie bereavement support service **https://www.mariecurie.org.uk/help/support/bereavement** Telephone: 0800 090 2309 (or you can book for them to call you).
- Childhood Bereavement Network for support for children or young people when someone close to them has died. Telephone: 020 7843 6000. **https://childhoodbereavementnetwork.org.uk**
- Child Bereavement UK for support for children and young people (up to the age of 25) when someone important to them has died or is not expected to live. They have helpful information for preparing a child when someone close to them will die and information on developmental stages of understanding death and dying. Telephone: 0800 02 888 40. **https://www.childbereavementuk.org**
- Winston's Wish is a childhood bereavement charity providing advice, support & resources for grieving children. They have information for teenagers, parents, grandparents and about starting memory boxes. Telephone: 08088 020 021. **https://www.winstonswish.org**

Acknowledgements

This information was written by:

- Catherine White, ICUsteps
- Dr Kathryn Mannix, retired palliative care doctor
- Professor Natalie Pattison, Professor of Clinical Nursing, University of Hertfordshire/East and North Herts NHS Trust
- Dr. Joe Cosgrove, Consultant in Anaesthesia & Intensive Care Medicine, Newcastle upon Tyne NHS Foundation Trust.

With thanks to:

- Jeanette Foley, Deputy Chief Nurse, Organ and Tissue Donation and Transplantation, NHS Blood and Transplant
- Dr Polly Fitch, Consultant Clinical Psychologist, Adult Critical Care Unit, Royal London Hospital
- Kirsti Meachem, relative of an ICU patient
- Dr. Victoria Metaxa, Consultant in Critical Care, King's College Hospital
- John Richardson, Assistant Director, Organ & Tissue Donation & Transplantation, NHS Blood and Transplant.

Thank you for permission to include some text from:

- 'Care and Support as the End of Life approaches in Critical Care' written by Susan Armitage, Donna Barnett and the Critical Care End of Life Team from Sheffield Teaching Hospital NHS Trust
- 'Bereavement in Critical Care: what happens after a person dies', written by Professor Natalie Pattison and the ICU & Palliative Care team from Royal Marsden NHS Foundation Trust.

ICUsteps is a charity set up by former intensive care patients and their family members in partnership with healthcare professionals. We aim to promote better support and rehabilitation for patients and their relatives after a critical illness.

You can find out more on our website. If you found this booklet useful, you can help us continue our work through making a donation through our website.

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Registered Charity No.1169162

Rev: 2307PG

ICUsteps

The intensive care patient support charity