How to prepare for the death of a friend or relative receiving end of life care

If a friend or family member is nearing the end of their life and receiving care in a hospice, hospital or care home, or even in their own home, it can be a very difficult time for you. This is all the more challenging during the coronavirus pandemic. We have provided some information here to help you through this challenging time, covering the following areas:

1. Advance care planning
2. Visiting people before they die
3. Practical care for someone in end of life
4. What to expect when death is near
5. Where to go for futher support

1. Advance Care Planning

Advance Care Planning involves making decisions now about an individual's future care. Health and social care professionals, such as doctors or nurses, can talk through the options and what sort of care might be needed in the future. It can be helpful to discuss these options with loved ones, family and friends.

Across north east London, our approach to Advance Care Planning is to use Coordinate My Care (CMC), an innovative NHS service that builds medical care around an individual's future care wishes. It helps to create the plan with health and care professionals which is recorded in CMC. We then share it with all the healthcare professionals who might treat the individual, so everyone knows exactly what they want.

For more information visit www.coordinatemycare.co.uk/for-patients or read our guide on Advance Care Planning.

2. Visiting people before they die

During the pandemic, to protect people and to prevent the spread of the virus, there will be limitations and restrictions on visiting people who have COVID-19 if they are in a care home, hospice, hospital or other care setting.

We realise that this could make the situation more distressing for you and our thoughts are with you during these challenging times. Staff are doing all they can to protect you, your family and their friends and provide the best care possible.

The government has announced that it will allow people the chance to say goodbye to those dying from coronavirus in hospitals and care homes "wherever possible."

However, you will need to check with the care home, hospice or hospital first to find out the latest situation.

It is so important that care homes, hospices, hospitals, and other care settings have all your correct contact details and are clear on who to contact when an individual reaches their last days and hours.

If you or a relative are going into hospital or are in a care or health setting it may be difficult for you to connect with friends and family during the pandemic with reduced visiting rules. If possible, having a phone or a tablet, a charger and available data would be recommended. If you are struggling to find a way to connect with relatives you can email **info@ageukeastlondon.or.uk** for help.

3. Practical care for someone in end of life

This section outlines what to expect and what can be done to help make the experience as comfortable as possible for someone approaching the end of their life.

If someone is in a hospice, care home or hospital, professional health and social care staff will provide the best support possible and will be taking care of the areas mentioned below to care for your friend or relative.

If an individual has chosen to die at home, there are some useful tips here on how to make things more comfortable for them. You should always seek advice from your health and social care professional.

Communication and environment

When approaching the end of life, people often sleep more than they are awake and may drift in and out of consciousness.

Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting.

This can reduce anxiety even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.

Feeling sick

Sometimes people can feel nauseated or sick when they are dying. If vomiting, and unable to sit up, turn the person on their side to protect their airway. There are medicines that can be given to help relieve this.

Moving

The person will require washing at least once a day and regular turning every 2-4 hours to protect their skin from developing pressure sores.

Alternate their position from lying on their back to each side. You can use pillows or rolled up towels to support them and also to support under their arms and between and under their legs. When you are washing the person, look for signs of redness, or changes in the colour or appearance of their skin. Check the back of the head and ears, the shoulder blades and elbows and the base of the spine, hips and buttocks, ankles, heels and between the knees.

Breathlessness and Cough

Breathlessness and cough can be another cause of agitation and distress and it can make it difficult to communicate. Don't expect the person to talk and give them time and space to respond. Reassure them that the unpleasant feeling will pass.

You can offer reassurance by talking calmly and opening a window to allow fresh air in. If possible, sit the person up with pillows rather than lying flat as this can help the sensation of not being able to breathe.

Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing. There are medicines that can be given to help dry up secretions if it is a problem.

Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. It can be frightening to look after someone who is restless. It's important to check if the cause is reversible like having a full bladder or bowel which can be reversed by using a catheter to drain the urine or medicines to open the bowels. Your health team can assess if this is necessary.

Check if their pad is wet to see if they are passing urine or if they are opening their bowels. If it's not either of these things, there are things you can do and give to help. Try to reassure the person by talking to them calmly and sitting with them. Touch can be effective in doing this too. There are also medicines that can be given to help settle and relax someone.

Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. Even though we expect someone to go to the toilet less as they eat and drink less, contact the health care team that is looking after them if they have not passed any urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled.

Mouth care

While people rarely complain of thirst at the end of life, a dry mouth can be a problem due to breathing mostly through their mouth.

It's important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush whether he or she is awake or has lost consciousness.

Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens tell the person's healthcare professionals as it can be treated easily

Washing

Sometimes it may be too disruptive for the person to have a full wash. Just washing their hands and face and bottom can feel refreshing. To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the bottom half.

Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly. Only expose the parts of the person's body that are being washed at the time – you can cover the rest of their body with a towel. This helps to keep them warm and maintains their dignity.

Eating

As the body shuts down it no longer needs food and fluid to keep it going. When a person is dying, they often lose their desire to eat or drink and finally their ability to swallow. They can lose weight rapidly.

This is often difficult to accept because we often equate food with health and feeding people as an act of love. However, hunger and thirst are rarely a problem at the end of life.

Continue to offer a variety of soft foods and sips of water with a teaspoon or straw for as long as the person is conscious (but allow them to refuse it). It's important not to force food or drink onto someone who no longer wants it. Remember to sit them up when offering food and fluids to avoid choking.

When a person is no longer able to swallow some people want them to have fluids via other routes like a drip, but at the end of life this offers little, if any, benefit. The body cannot process the fluid like a healthy body can and it can be harmful to artificially feed and hydrate. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems.

4. What to expect when death is near

In the last hours, breathing may become shallow and irregular. Sometimes there are pauses between breaths that become longer until the last breath is taken. They may drink less and become incontinent.

It is normal for them to be restless and agitated, however if you are worried, a health and social care professional can give medication to alleviate this. If they are being looked after at home, please contact your local district nursing services.

Their arms and legs may become cool to the touch and blue in colour as a result of blood circulation slowing down. The skin may also start to become dry or clammy.

Talking to them, telling them you love them and generally keeping them calm at this stage is important. Remember, this is a natural process and they will appreciate you being there with them.

Understanding what happens when someone is approaching death will help you anticipate the care they need, the things that happen during that time and what support you or others can give them.

As their health gets worse, they will become weaker and will need more support from those caring for them.

Keeping in contact

Again, as mentioned above, it is vital that the health and social care staff have your correct contact details so they can keep you up-to-date.

Everything will be done as far as possible to give you the opportunity to visit your friend or family member before they die.

However, during the pandemic, if you are self-isolating for example, you may need to consider options such as using online technology to say goodbye to a friend or family member, to help keep you and others safe. This should be discussed with the hospital, hospice or care home.

5. Where to go for futher support

Please also see the information and support in the following guidance packs:

- Advance Care Planning
- What to do if a friend or relative dies
- Bereavement Support Services

You can also get more information and support from Dying Matters: www.dyingmatters.org/overview/need-support