

COVID-19: end of life care at home

Guidance for family members and friends



During outbreaks of COVID-19 families may face the daunting and sad prospect of having to care for a loved one at home at the end of their life. You may find yourself in this situation if an older relative or friend has COVID-19 and chooses to stay at home, or if facility-based care is unavailable. This guidance is focused on end of life care for someone with COVID-19 but much of the information is relevant for those caring for someone with other conditions.

This document includes:

- Providing physical care and managing symptoms and phases of dying
- Supporting emotional wellbeing
- Supporting spiritual wellbeing
- Looking after yourself
- Coping with grief and bereavement

Care at home

With COVID-19 spreading around the world and health systems struggling to cope, there may be situations where facility-based care is unavailable or not accessible due to cost or distance to a facility. In other instances, an older person diagnosed with COVID-19 or suspected to have the virus, may choose to stay at home.

Choosing to stay at home

If the older person chooses to stay at home, family members and any health or social care workers involved in the person's care, must be confident that the older person understands the implications of their decision to stay at home, including a greater chance of dying. It is important that the older person is deemed to have full mental capacity when making their decision.

Respecting older people's wishes

If your older relative or friend is not able to express their wishes, you should only decide to keep them at home if you have previously written or clear verbal instructions from your loved one that they want to stay at home. You are also allowed to make decisions for the older person if you have legal lasting power of attorney, if such a system is in place in your country. Any decisions must respect any known wishes of your loved one.

Making decisions together

In many places, family and other members of the community may usually be involved in making decisions around health and the end of life. During these discussions, the older person must be fully involved and empowered to make decisions. In the context of COVID-19 it is important that any discussions with others, happen in accordance with physical distancing.

Asking for help

If you are caring for your loved one at home and you are concerned they may die, reach out to your community for help. Ask community members or other members of your household to take on daily tasks, such as shopping, fetching water or firewood, and looking after any children or other people you usually have responsibility for. Community members must find ways to keep physical distance while providing you with support.

Health workers, including palliative care and hospice providers, can also help. Your relative or friend may not die as a result of COVID-19 if they stay at home. However, if they are older or have an underlying health condition their likelihood of becoming seriously unwell and dying is increased. Try to contact community health workers or caregivers, by phone if possible, and ask if they know of local palliative care providers who can give you information and help you make plans. Palliative care providers will be able to give advice and support on how to care for your relative's physical health and their emotional and spiritual wellbeing. They will also be there to support you, including with grief and bereavement.

Providing physical care and managing symptoms

Managing symptoms

The main symptoms of more serious illness with COVID-19 are difficulty breathing, fever and cough. Older people may experience increased anxiety,

confusion and delirium. There are things you can do to support the older person you are caring for and manage their symptoms.

Medicines

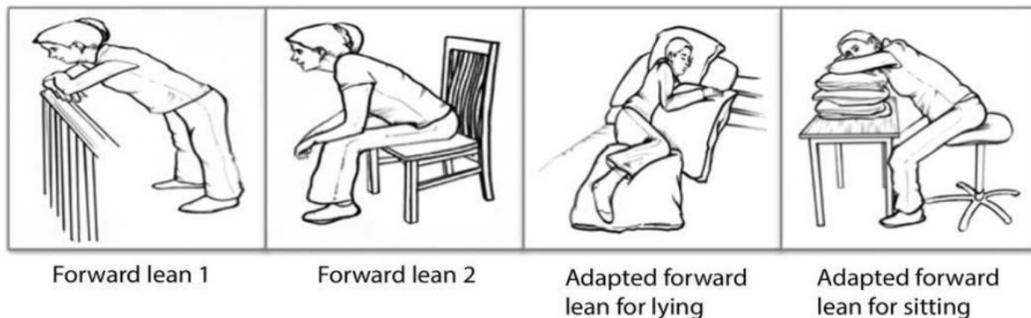
Medicines may be available to ease some of the symptoms of COVID-19 and their impacts, for example shortness of breath, pain, agitation or distress.

1. Talk to your doctor, palliative care provider or other health worker about what you need.
2. If palliative care providers or health workers need to visit your loved one at home to administer medicines, ask them to take precautions - wearing protective equipment (including a mask and gloves) and washing their hands on arrival at your house.
3. Ask them to explain to you and your loved one what medicines are being used, what they are for and how frequently they will need to be taken. It is important that you understand so that you can help your loved one to take any necessary medication.

Breathing

Difficulty breathing will be a major symptom of COVID-19 up to the end of life. The feeling of shortness of breath can be distressing for the older person. It can also be hard for you to see your loved one struggling in this way. Below are some suggestions to help you manage this symptom:

1. To ease the feeling of chest tightness and shortness of breath, try to help your loved one sit or be propped up in bed. This will help use all parts of the lungs. If possible, ask your palliative care provider or health worker about the best way to do this. Remember to ask your loved one which positions are most comfortable.



Source: Marie Curie

2. Try to keep the older person's face cool. You can use a cloth dipped in cold water to wipe the forehead and around the nose and mouth.
3. Keep the room well ventilated by opening a window or door. Avoid using a fan, as this will blow the virus around the room, putting others at greater risk.
4. Talking to the older person in a calming voice can help to lessen anxiety. You could also try to calm your loved one by helping them to do some breathing exercises. For example, inhale through the nose for several

seconds with the mouth closed, then exhale slowly through pursed lips for 4 to 6 seconds. Demonstrate first and ask your loved one to copy you.

5. Noisy breathing is caused by secretions. This can be distressing for you to hear but does not cause your loved one pain and will not make breathing difficulties worse.

Fever

1. If you have a thermometer, try to measure the older person's temperature to check for fever. You can also check to see whether their chest or back feel hot to touch.
2. If the older person has a fever, they can take paracetamol.
3. You can also use a cool cloth on the forehead or sponging with lukewarm water to help cool down the fever.

Cough

1. Throat lozenges or a teaspoon of honey can be soothing and help ease a cough.
2. Where possible try to prop your loved one up in bed. If they are lying flat, they will not be able to cough properly.

Anxiety, confusion and delirium

1. Talk to your loved one about any concerns or anxieties they have. Speak clearly.
2. Explain where and who they are, who you are and what your role is.
3. Ensure the room is well lit whenever possible.

Restlessness

Towards the end of life, your loved one may make repetitive motions such as pulling at bed linen or clothing. This is due in part to a decrease in oxygen and there is no need to try to restrain these movements.

1. Speak in a quiet, natural and comforting way.

Eating and drinking

Towards the end of life, the older person you are caring for may not be able, or want to, eat or drink very much.

1. Try to give small sips of water from a cup, spoon or straw, depending on the person's ability. Try to help them to sit up a little or prop them up.
2. If the person is not able to drink, or is only taking very small amounts of water, try to wet their lips and mouth every so often with a soaked sponge or cloth.
3. Lip salve or Vaseline can help with dry or cracked lips.
4. Encourage your loved one to eat and drink independently or with support for as long as possible. However, do not worry too much about trying to get your loved one to eat. If they want to eat:
 - Ask your loved one what they would like.

- Colourful foods and soft foods like yoghurt or loose porridge may work well.
- Try small amounts of food.
- Place food in the side of the mouth to avoid choking.

Toileting

Changes in people's urine and bowel function are normal at the end of life. People may lose control of urinary and/or bowel functions. The amount of urine and stool being passed may decrease. Urine might become darker in colour. It might be useful to keep a diary of toileting habits to note any changes and to help you provide care.

Toileting can be a particularly sensitive and personal issue. Talk to your loved one about how to support them with this, whether they would prefer a man or woman to help, for example.

1. If your older relative is unable to get up from their bed, you will need to help them with toileting. Try to have some incontinence pads or adult diapers at home for them to use. Change these regularly and wash and dry your loved one's skin carefully.
2. If these are not available, older men can pee into a large empty jar. It may be more difficult for older women. If they are unable to use a bucket or bowl, you can put a folded towel or cloth between their legs. This should be changed whenever used and washed, and left out to dry in the sun.
3. For bowel movements, if nothing is available, put some newspaper under your older loved one to catch stool. Remove this immediately and empty into a toilet if possible. Do not put the newspaper into the toilet. If you cannot dispose of it in this way, put everything into a plastic bag and tie it tightly before disposing of it in your garbage.

Moving

Towards the end of life, particularly when your loved one is unable to get up from their bed, it will be important to keep them as comfortable as possible. The same principles apply if your loved one is sleeping at floor level.

1. Try to arrange their pillows so they are propped up, rather than lying flat.
2. Try to help them move position, if possible, every two hours to avoid pressure sores.

How to move someone in bed

Rolling on to the side:

1. Stand close to the bed. Remove bedding except one pillow. Make sure your loved one's clothes are covering them, and that they stay covered while you move them.
2. Cross one leg over their body towards you.
3. Move their arm over their chest and towards you. Let them know when you are ready to roll them and explain you'll be rolling them towards you.
4. Put one hand on their hip and the other behind their shoulder, gently pull them in your direction so they roll forward. They are now lying on their side.
5. Place a pillow behind them to prop them up and cover them with their bedding.

Rolling from side to back:

1. Remove any pillows.
2. Go behind them and put one hand on their hip and the other on their shoulder.
3. Gently pull them towards you so they roll on to their back.

Smoother rolling:

1. Place an extra sheet underneath your loved one.
2. By pulling this sheet, you can move your loved one from right to left and from top to bottom as it creates a smoother transfer for you and the older person.

Supporting emotional wellbeing

Alongside providing physical care and managing symptoms, try to support your older relative's emotional wellbeing. Ask your palliative care provider or health worker for advice.

1. Ask your loved one how they are feeling and what they want.
2. Physical contact is important and can be comforting for both you and your relative. However, in the context of COVID-19 you need to wear a mask and gloves to protect yourself. Explain to your older relative why you need to do this. If you have to touch your loved one without gloves, wash your hands immediately before and after.
3. If possible, ask your loved one to wear a face mask when they are around you or others in the home. This could be a cloth face covering, if a mask is not available. Remember to wash or dispose of the mask or cloth carefully after use, to avoid transmitting the virus.
4. Talk about any ongoing responsibilities or projects that your loved one is concerned about and plan for after they have died.

5. If your relative is no longer able to communicate verbally, try to use other forms of communication to understand how they are feeling, for example, writing messages, showing pictures or pointing.
6. If you are unable to communicate with them at all try to support their wellbeing with things they would usually like or enjoy, and ways they find to relax.
7. Try to spend some time relaxing together, doing something your older relative says they would enjoy. Perhaps listen to some music or the radio, read the newspaper talk with each other or just spend some quiet time sitting together.
8. It is likely your loved one will start to sleep more towards the end of their life. They may also become more difficult to rouse. Try not to worry about this, it is natural. You can stay with your loved one while they are asleep and keep talking to them. It is likely they will be able to hear you.
9. Try to make your loved one's room, or the space they are in, as comfortable and pleasant as possible. They might want to be able to see photos of family and friends.
10. If possible, try to ensure your relative can stay in contact with other family and friends, while maintaining their isolation. People could phone, make video calls or write letters. If your loved one is able to speak, consider recording their voice, perhaps reciting a favourite poem or a message to their family and friends.

Supporting spiritual wellbeing

Spiritual support is important for many people at the end of life. Spirituality relates to how we experience, express or seek meaning and purpose in life and death, and the way we connect with ourselves, with others, with nature and with what we hold sacred. There are things you can do to support your loved one's spiritual wellbeing at the end of life. Your palliative care provider or health worker might be able to provide further advice.

1. If possible, ask your loved one about their wishes. You could try to help them make a living will. A widely used approach is to document *five wishes*.

Five wishes

Wish 1: The person I want to make care decisions for me when I can't

E.g. Who I would like to speak for me if I can no longer speak for myself

Wish 2: The kind of medical treatment I want or don't want

E.g. whether I want medicines to relieve symptoms

Wish 3: How comfortable I want to be

E.g. instructions for bathing and grooming

Wish 4: How I want people to treat me

E.g. whether I want someone to pray with me

Wish 5: What I want my loved ones to know

E.g. my wishes for after my death, any feelings or memories I want to share with my family

2. Religion, spiritual or ethical beliefs may provide a great source of comfort, inspiration, hope and peace in the lead up to death. However, for some people, this might not be the case. They may question their faith or fear death because of their beliefs.
3. Some people might like to connect with or seek counsel from someone who shares their beliefs, or who they feel could provide guidance: a minister, priest, imam or humanist for example. If this is the case, try to find a way to enable this connection, while maintaining the person's isolation. This could be by phone or you could ask this person to write to your loved one.
4. Ask your older relative if there are specific religious or other spiritual practices they would like to follow in the last stages of their life, and do your best to facilitate this, while following the necessary restrictions in relation to COVID-19.
5. For some people, connections with their families, communities, places and things they enjoy, provide meaning. Talk to your relative about this to understand how to support them.
6. Many people who are dying reflect on their lives and what they have achieved. For some people this can lead to feelings of regret and dissatisfaction. Talk with your loved one about the things they have done that have had meaning and made a positive impact on your life. This can help them realise their greatest legacy is what they did with their family or community, bringing great comfort.
7. Try to talk to your older relative about any particular wishes for their funeral, such as where or how they would like to be buried.

Looking after yourself

It is important that you look after yourself at this time and that you feel supported.

1. While you are caring for your older relative, remember your own risk of infection, particularly if you are older or have underlying health conditions.
2. Take precautions by wearing a mask and gloves while providing care and washing your hands regularly.
3. Take care around other household members. Make a timetable for using shared space to limit contact, for example cooking areas and bathrooms.
4. If possible, use a separate bedroom and bathroom. Do not share dishes, cups, silverware, towels, bedding, or electronics with your loved one.
5. Clean and disinfect surfaces that are handled frequently every day. This includes tables, doorknobs, light switches, handles, toilets, taps, sinks, and electronics.
6. Make sure you look after your own health. If you are taking any medication, remember to keep doing this and try to have two weeks supply available.

7. Take some regular exercise and stay active. Find ways to do this around the house and in the garden if you have one.
8. Keep your diet as healthy as possible and stay hydrated.
9. Get adequate rest and do what you can to ensure a good night's sleep.
10. It is important to stay connected with friends, family and other carers, particularly at such a difficult time. Try to find ways to stay in touch, by phone, for example.
11. Take a break. You may find you are having to do more, particularly if other carers who usually support you are not visiting. Do what you can to make some time for yourself. Try to schedule small amounts of relaxation time into your day.

Coping with grief and bereavement

The death of a loved one can be one of the hardest situations people face, bringing bereavement and grief. The restrictions that the COVID-19 pandemic is causing may bring further challenges if you have lost a loved one. Physical distancing or isolation rules mean you may not be able to see family and friends for support or you may be unable to follow funeral or burial practices as you usually would. It is important to recognise your feelings and to seek support where you can.

1. If you have cared for a loved one who had COVID-19, you need to isolate yourself at home after their death, in case you have acquired the virus yourself.
2. Isolation following the death of your loved one may make your feelings of grief and loneliness worse. Try to stay connected to friends and family by phone or writing.
3. Rest and get some sleep at night.
4. Get some fresh air. Open a window or go out into your garden if you have one.
5. Maintain a daily routine. Get up and get washed and dressed. Try to stick to regular mealtimes.
6. You may not feel like eating but try to have healthy meals. Avoid overuse of alcohol, tobacco and drugs.
7. Do regular exercise around the house or in the garden if you have one.
8. If it is comforting, have photos of your loved one up in your house.
9. You may find it helpful to write a message for your loved one, or to speak to them, in your head or out loud.
10. Try not to feel guilty or angry when your grief feels easier to manage. Having better and worse days is a normal part of grieving. Feelings of relief that your loved one is no longer suffering are also normal.
11. Try not to look for something or someone to blame as this can reinforce unhelpful thoughts and emotions.
12. It is common to see, hear or feel the presence of someone who has died. This may be more likely given you have cared for your loved one at home

and now have to isolate yourself there. Try not to worry if this happens. It is a common part of grieving.

13. Seek support from your palliative care provider or other health workers. It will be important to share your feelings.

References

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Find out more:

[Helpage.org/coronavirus-COVID19](http://helpage.org/coronavirus-COVID19)

[Thewhpca.org/covid-19](http://thewhpca.org/covid-19)

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Published by HelpAge International on May 2020 PO Box 70156, London WC1A 9GB
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