

Family, Friends and Carers



Understanding your relative's hospital stay and how it felt

If a family member or close friend has been in hospital with COVID infection, this will have been a very stressful time for you, as well as for them.

You probably felt very anxious and feared the worst at times, made harder by the visiting restrictions at the hospital and not being able to see your relative to offer them comfort or explain what was going on. You won't have known the hospital staff caring for your relative and you probably had limited access to medical information and updates when you wanted a full understanding of what was happening.

Being in hospital with COVID is a frightening experience. Patients who spend time in Intensive Care Unit (ICU) receive a number of tests and treatments within a stressful environment. It may have been scary for them, with hospital staff wearing gowns, masks and visors.

ICU patients often have unusual experiences such as hallucinations (seeing or hearing things that are not there) or delusions (strange beliefs about what is going on in the hospital). They can have difficulty knowing what is real and what is not. This is because of confusion or delirium caused by their illness, the noisy ICU area or ward and the medication they may have been given.

They may have seen or heard distressing situations during their time in hospital and may not have been able to, or wanted to talk about it. Confusion, hallucinations and delirium are usually temporary side-effects. It does not mean anything has gone wrong with their mind, but it can be difficult to listen to and understand.

Feelings you might be experiencing now they are home

Your relative or friend may still have physical and psychological difficulties once they come home or during their recovery at home, if not hospitalised.

Physically they may still have breathlessness, feel very weak due to lack of appetite, stiffness in their joints or fatigue (high levels of tiredness). Some may be low in mood, anxious or irritable during their recovery period, or they may experience some problems with memory and thinking or sleeping problems with nightmares or flashbacks of their hospital experiences (these can be very vivid and seem very real). They may also worry about their recovery, especially if they were fit and well before their COVID illness.

You may find that for a while, they may need more understanding and support from you than usual. You may need to find a balance between supporting them, and also encourage them to become fully independent again as soon as possible. This can be a demanding time for you, it's normal for relatives to worry about whether they will be able to cope with providing support but your support and encouragement will be a key influence on their recovery.

Talking to them positively about being discharged from the hospital may help them see the positive side to their recovery process and how they are gradually achieving this. Some people find it difficult to accept that they survived COVID and are now able to begin their recovery.

Relatives and friends can experience as much, and sometimes even more, stress than the patients themselves in serious illnesses like COVID. You may have feared the worst, felt helpless, tired, anxious or upset. This can continue for you during their recovery too.

In order to support your family member, relative or friend who has been ill, you also need to take care of yourself. We know that families also suffer a lot of stress when they have a relative in hospital.

Make sure you look after yourself too

In order to support your relative or friend who has been ill, you also need to take care of yourself. Families suffer a lot of stress when they have a relative in hospital. Sometimes relationships may be strained after hospital discharge because the person you are supporting may not realise how stressful it has been for you, or you may not want to upset them further by telling them about your own experience or what you remember of theirs.

Your relative or friend may also be frustrated by their own limitations, physical or psychological symptoms, or struggling with their concentration, memory and emotions. It takes time to adjust to a new 'normal'. This all has an impact on you too.

The most important things that you can do for you both are:

- Recognise the impact that supporting your relative is having on you.
- Don't blame yourself – you are human too!
- Take time out to do things for you.
- Speak to someone if you're finding it difficult to managing your daily tasks with your caring duties. There are many support helplines and local charities available for carers to get help and support too.

Self-care

- Take care of your health, make sure you are eating and sleeping well.
- Take regular breaks, give yourself time to rest and relax.
- Spend time with your friends (if not in person then by phone or video call).
- If you're able to go for a walk, exercise is good for both physical and mental wellbeing.
- Confide in trusted friends or family about your own feelings, there's a lot of truth in the saying "a problem shared is a problem halved".
- Ask for help – You don't have to do everything alone. Ask family and friends, join a support group, and make use of community support and online resources.

Communication between family and friends and the person recovering

- Give yourselves time to talk about your experiences, if ready.
- Allow time to respond, it can take time to give an answer or understand what has been asked.
- Sitting and listening, is sometimes all you may need to do.
- Listen to how they might want you to help them.
- Try not to do too much for them. You may want to, but it's better for them to do things for themselves as they feel able.
- Encourage them to be active or be active together.
- Respect their wishes so they can maintain their self-esteem.
- Respond sensitively, they may find it difficult to accept how things have changed.
- You may have to do things differently for a while or at a slower pace.

- Write a list or set reminders e.g. alarms on your phone, reminders on your home virtual assistant device (Alexa/ google home).
- Offer support and reassurance but allow them space too, this is equally important for you.
- Read the information in this website to help you both.
- Have a support network that you can talk to.

You and your partner

If the person who has been ill is your partner, this can have an impact on your relationship. You may already have a lot to deal with (work, finances, family, and your own health) but illness in the family can make things harder. Suddenly there are even more things to do, appointments, visits from health care workers, loss of routine, and loss of independence. This can put a strain on your relationship, although some find it brings them closer together.

People may find it embarrassing to talk about personal issues and difficulties they face, for example with self-care, change in dependency or intimacy.

They may also experience changes to their mood and pain can also make people more frustrated, angry, upset or depressed.

Be patient, this should get better as they recover.

What can I do if I'm feeling overwhelmed

- Prioritise things that are most important at the present time.
- Plan your time in the day or over a week. Don't overload yourself.
- Allow yourself time to rest.
- Problem solve, work together to support each other through the recovery process.

- Allow the person you are caring for to do things in a way and at a pace that works for them, this may be the new 'normal' for a while. Give yourself time to have a break, away from your relative and reach out for further help if needed.
- Seek support from your General Practitioner (GP) who will guide you to local services, support and psychological (or "talking") therapies available free on the NHS.

You can access these services online or over the telephone through your local "Improving Access to Psychological Therapies (IAPT)" service.

You can also refer yourself to your local talking therapy (IAPT) service without seeing your GP. Find your local talking therapy (IAPT) service here: nhs.uk/service-search/find-a-psychological-therapies-service

If you need to access to further advice and support

The NHS also offers urgent mental health helplines.

You can call them for:

- 24-hour advice and support – for you, your child, your parent or someone you care for help to speak to a mental health professional
- an assessment to help decide on the best course of care

See – nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline

There are a number of national services run by voluntary organisations that offer confidential advice from trained volunteers. You can contact them 24 hours a day/seven days a week.

- Call **116 123** to talk to [Samaritans](https://www.samaritans.org), or email: jo@samaritans.org for a reply within 24 hours
- Text "**SHOUT**" to **85258** to contact the [Shout Crisis Text Line](https://www.shoutcrisis.org).

Other Resources

- [icusteps.org](https://www.icusteps.org) – a registered charity run by former intensive care patients and relatives, improving the care and support available to patients recovering from critical illness during their long recovery.
- [carersuk.org.uk](https://www.carersuk.org.uk) – advice, information and support for carers and young carers with caring responsibilities
- [nhs.uk](https://www.nhs.uk) - the NHS website for England, providing information on health, treatment and services
- [youngminds.org.uk](https://www.youngminds.org.uk) – a comprehensive site supporting the mental health of young people in times of crisis.