Caring to the end

Help and support when your partner, relative or friend goes into hospital, and may be approaching the end of their life

The support I received helped me through one of the most difficult times of my life.

Are you supporting an adult patient – a relative, partner, friend or neighbour – who has been admitted to hospital and who may not have long to live? If so, read on...
Who is this booklet for?

This booklet is for anyone who is supporting an adult patient – a relative, partner or friend – who has been admitted to hospital and who may not have long to live.

At all times I was included in the conversations, kept informed, and treated as part of Mum's care team.
We use the word ‘carer’ to refer to anyone providing unpaid, informal support or care to a relative, partner, friend or neighbour who is disabled, frail or ill. The carer may have been looking after the patient for a long time, but sometimes a person becomes a carer overnight when their family member or friend is suddenly admitted to hospital.

If you are supporting someone who seems to be nearing the end of their life, and who has gone into hospital, you can make a big contribution to the care they receive, and can help to make sure that they are as comfortable and well-looked after as possible. You know the person well and can tell the doctors and nurses about them. You can keep the person company and help to reassure them if they are feeling anxious or frightened.

If you have been caring for this person for some time, you have probably become an expert in looking after them. Don’t be afraid to ask questions and make suggestions, especially if you are feeling worried.

The hospital staff will be doing their best to look after your family member or friend, and they should welcome you as a member of the care team.

Make yourself known and explain who you are to the ward clerk and the doctors, nurses and health care assistants who are looking after your relative or friend, and find out their names. Make sure they know how to contact you at all times.
Can the patient answer questions and explain things to the doctors? If not, do you have information which it would be useful for the hospital team to know?

If the patient has dementia or a learning disability, or has any difficulties with communication, you may be able to communicate with them more easily than a doctor or nurse who has not met them before.

The patient may be too ill, tired or confused to remember their medical history or explain their symptoms to the doctor. You may be able to tell the team about the patient’s usual medication, and whether they have been ill recently, before they came into hospital. You can let the team know about any other health problems – including mental health issues – which affect the patient.

You can let the team know if the patient has hearing difficulties or poor eyesight, if they need help with eating and drinking, or supervision to take their medication, or if they do not speak English very well and need an interpreter to explain what is going on. If the patient appears confused, you can say whether this confusion seems to have got worse since they were admitted to hospital.

You may find it useful to write down this information about the patient using the *This is me* leaflet available from the hospital or from the Alzheimer’s Society. See page 18.

They listened to me and changed my husband’s medication based on the information I provided.
Has anyone told you what is happening, and explained to you that your relative may be going to die?

The doctors and nurses will do their best to look after your relative, but at a certain point they may realise that this person is not going to recover, and is going to die quite soon. It is now their job to try to make the last days or hours of the patient’s life as comfortable and as pain-free as possible.

Of course, a doctor does not always know for certain whether someone is about to die, but it is helpful for the family to understand that it is a possibility. Some carers say they had no idea that their relative was dying, and it was a terrible shock. They say they wish they had known what was coming, so that they could prepare, and say their goodbyes.

Doctors and nurses sometimes feel uncomfortable talking about death and dying, in case it upsets the patient and their family. They may not mention it at all, or they may drop hints, without explaining clearly.

Don’t be afraid to ask the hospital staff to explain more clearly if you don’t understand what they are trying to tell you.

The consultant was brilliant. He said to my Dad: 'You're not going to recover from this. It may be a few weeks or a few months'. He explained the treatment options and said 'I need to know how you feel about that'.

Nobody told us my husband was dying. They just said, 'Don’t worry about getting the stairlift installed.'
The National End of Life Care Strategy says that ‘carers should be included in any planned discussion with the dying person’ but some carers say that they were not kept informed or included.

Sometimes hospital staff say they cannot include the family, as it would breach ‘patient confidentiality’. If the patient says that they don’t want their family involved, these wishes must be respected. Sometimes however, the patient is too ill to be able to give or refuse their consent.

In fact, recent guidelines encourage health and social care professionals to share information if it is in the ‘best interests’ of the patient, and so long as the patient has not refused this permission.

Make it clear to the staff that you wish to be kept informed and included.

Let them know if you have previously discussed with your family member or friend how they wish to be cared for, and whether their wishes have been recorded in a document such as an advance decision or a lasting power of attorney for health and welfare.

The palliative care team were marvellous. They listened, consulted and devised a personal care plan which met everyone’s requirements.
All carers should have the chance to keep their friend or relative company at this critical time. Most hospitals make special arrangements for people visiting a patient who is likely to die, for example, a special parking discount, and flexible visiting hours.

As the patient’s death gets closer, you may wish to stay overnight. Some hospitals are able to offer you a more comfortable chair, somewhere to wash, a toothbrush and soap, etc.

Physical contact such as holding hands, and talking or saying prayers quietly, even if the patient seems unresponsive, can be soothing and reassuring both for the person who is dying and for their family.

If you have a disability, ask the team to make sure it is possible for you to stay close to and communicate with your relative, just like everyone else.

Let the hospital team know if you would like to stay involved in the physical care of your relative or friend. This may not always be possible – if for example there is a risk of infection – but it is worth asking about.
Seeing a family member or close friend very ill, and possibly approaching death, is a tough experience for most people. You may feel sad, frightened, anxious, exhausted and overwhelmed. Practical and emotional help and support is available for you as a carer – but do you know where to find it?

There may be someone in the hospital whose job it is to provide information and support to carers. Different hospitals offer this support in different ways. It may be provided by a social worker, by a ‘carers’ champion’ or a carers’ support worker. Sometimes the Patient Advice and Liaison Service (PALS) takes on this role. Ask the nurses or other staff on the ward who you should talk to, and find out if there is an information pack for carers.

If there is no carers’ support service on site, you can get practical, financial and emotional advice and support from your local carers’ centre or hospice. See page 18 for organisations which can help.

You and your family may also find it helpful to talk to a hospital chaplain. Chaplains can offer comfort and support to people from different faith communities, as well as those who have no religious faith.
...about the care and treatment your relative or friend is receiving?

If you do not feel happy with the care and treatment your relative or friend is receiving you should let the hospital team know about your concerns. It is best to speak up and express your worries now. This will give the team the chance to explain why they are doing things a certain way, or to put things right if something has gone wrong. Talking to the team should help to put your mind at rest.

First of all talk to the nurses, for example, the ward sister, charge nurse, or the matron. If they cannot help, talk to the doctor who is supervising your relative’s care and treatment. Ask when he or she will be available to talk to you, and make an appointment if necessary. It is a good idea to write some notes in advance, so that you don’t forget what you want to say, and to write notes afterwards, as a record of your conversation.

If you are still not satisfied after talking to the nurses and the doctor, go to the Patient Advice and Liaison Service (PALS) or the Patient Services Department. They will help you to make a formal complaint if you wish. You will need to provide all the relevant information – dates, times, notes of what was said at meetings, etc.

On the other hand, if you are pleased with the care and treatment your relative or friend is receiving, let the nurses, doctors and healthcare assistants know. Everyone likes to feel appreciated!

I cannot emphasise enough how grateful I am for the care we received.
What if...

...the person you are caring for is discharged from hospital?

If the doctors decide that the person cannot benefit from any further hospital treatment, it may be agreed that they can come home so that they can spend their last hours, days or weeks in familiar surroundings.

Some hospitals operate a system called ‘Rapid discharge home to die’, and will make every effort to discharge the person quickly if they are expected to die very soon.

Our son hated every minute he spent in hospital. He constantly asked when he could go home, but nobody suggested that this was possible. Eventually he was asked what he wanted, and again he asked to go home. The following day this was arranged and he died there that evening. We were greatly comforted that he could die at home.
You may be very glad that they are coming home, but it is important to know the facts. Are they being discharged because they are getting better, or because they are not going to get better?

It is vital that you are involved in the decision to discharge your relative home from hospital, above all if they may die very soon. If the hospital team suggest discharging the patient, make sure they explain to you what they are expecting to happen, what support you will get, and what you need to do if you are worried. If you don’t think you can manage at home, you don’t have to agree to this plan.

If your friend or relative comes home at this point, you should receive support from local health and social care services, to help you look after them and make sure they are not in pain or discomfort. For example, there may be frequent visits from the district nurse or community palliative care team. The exact services offered will differ from place to place. Make sure you are satisfied with the arrangements that have been made for the care of your relative at home before they are discharged from hospital.

Some patients may be discharged to a local hospice, or may be able to receive hospice care at home.

The hospice gave us a number that we could ring at any time if we were worried about anything.
If the person ...

...you are caring for dies in hospital, what happens next?

Care of the body after death

If the person you are caring for dies while in hospital, you may want to be involved in washing and caring for their body. It may be part of your religious duty to do this. Or, it may be essential in your religion that the body of the person who has died should be cared for by someone of the same sex. Let the team know what is important to you.

When Mum died they were happy for me to help with the last wash and then left me for some quiet time with her.

I was given the chance to meet the man who had taken care of my husband’s body after his death. He was very respectful and caring, and I found this a great comfort.
Hospital procedures and practical advice

When somebody dies in hospital, the hospital bereavement officer should meet the relatives, offer condolences and explain what is going to happen next and what the family need to do.

There are strict rules which the hospital must follow when a patient dies in hospital. The patient’s body cannot be released to the family before the medical certificate giving the cause of death has been signed by the doctor who was caring for this patient. Sometimes there may need to be an inquest, if the death was unexpected or if it is not certain why the person has died. This means there may be a delay. This can cause anxiety, especially if your religion requires the burial to take place quickly. The doctor who was caring for your relative, or the hospital bereavement officer, should explain to you the reasons for any delay.

The hospital bereavement service should also advise you about the practical steps you need to take, such as how to register the death and arrange the funeral, and who you need to inform. If you are on a low income, financial help towards the cost of the funeral may be available. For further information see page 18.
Caring for someone who is approaching the end of their life is extremely demanding, physically and emotionally. Many carers spend so much time and energy looking after the person they are caring for, that their own health suffers. It’s important to try and take care of yourself as well. Try to eat healthy food, get some regular exercise, and if you can, take some breaks from your caring role.

As the end approaches, try not to worry about getting all the usual tasks completed, for example, keeping everything clean and tidy at home. Don’t be afraid to ask for help from friends, family and colleagues. If you are working, can you take some time off?

What is the most important thing for you at this stage? For many people, it will be to make the most of the time that remains with the person who is dying.

After the person has died, you may feel at a loss, not just because you are grieving for someone you loved, but also because you have to adjust to a new role in life, now that you are no longer a carer. Health problems of your own may start to appear. It is a good idea to go to the GP and have a check up.

You may need emotional support as well as practical help. It may be comforting to talk to one of the hospital chaplains; they can also tell you about other local services including counselling and support groups. (See page 18.)

You and your family may not want this support immediately. You can get in touch with support services at a later date if you wish.
If you are a child or young person who has been caring or helping to care for a parent or relative who is ill or disabled, you deserve some extra support. There are young carers’ projects (for carers under 18) in many parts of the country, where you can meet other young people in the same situation, and get help and support. (See page 18.)

I’m 30 now but have been a carer since as early as I can remember. A few years ago I made contact with the local carers’ centre. They’re great and a real support.
All hospitals invite patients to tell them whether the care they received was of a good standard, but sometimes patients are unable to give this feedback themselves.

Let the hospital staff know your opinion of the care your relative or friend received in hospital, and whether you felt supported as a carer.

Some hospitals give patients and carers the opportunity to say whether you think the care is good or not during the patient’s stay in hospital. This could be through an interactive screen, a feedback postcard, a daily ‘relatives’ diary’ or a short face to face interview. It is really helpful for the hospital team to know whether you think the care is good or not, so that they can put things right if there is a problem. Don’t forget, compliments are just as important as criticisms.

You may be asked for feedback after the patient has been discharged from hospital, or after they have died. You may be invited to take part in a survey of bereaved relatives (the annual National Voices Survey, or a local version). These surveys provide valuable information about what people think of the care their relative or friend received at the end of their life, and are used to help monitor whether standards of end of life care are improving.
...in improving hospital care

You may get the chance to join a discussion group at the hospital, where you can describe your family’s experiences and make suggestions for ways in which services can be improved. You may be invited to come along to staff training sessions to talk about what matters to carers when their relative is in hospital at the end of their life. There may be an opportunity for you to become a ‘public representative’ on the Board of the hospital trust.

Your views really matter. By sharing your comments and your experiences, you can help to make sure that end of life care in your local hospital is as good as possible.

Since my daughter died I’ve had the chance to be involved in training doctors in how to provide good end of life care. Of course I’d give anything to have her back, but it’s comforting that something good is coming out of a very sad experience.
Where else can you get help?

General information and support for carers
Carers Trust: 0844 800 4361; www.carers.org
Carers UK: 0808 808 7777; www.carersuk.org
Carers Direct (NHS): 0300 123 1053; www.nhs.uk/carersdirect
Support for young carers: www.youngcarers.net

Caring for someone approaching the end of life
Find me help: www.dyingmatters.org
Help the Hospices: 020 7520 8200; www.helpthehospices.org.uk

Information, advice and support after someone has died
Government advice and information: www.gov.uk/after-a-death
Bereavement Advice Centre: 0800 634 9494; www.bereavementadvice.org
Cruse Bereavement Care: 0844 477 9400; www.cruse.org.uk
Support for bereaved young carers: 0808 808 1677; www.rd4u.org.uk

References
1. You can order a free copy of *This is me* by ringing 0300 303 5933, or download it from the Alzheimer’s Society website: www.alzheimers.org.uk
3. *Information: to share or not to share*. The Information Governance Review, Department of Health, 2013, pp. 45 and 119.
This booklet is for anyone who is supporting an adult patient – a relative, partner or friend – who has been admitted to hospital and who may not have long to live.

The booklet was created by NCPC as part of a project on *Involving and supporting carers in end of life care in acute hospitals* which was initiated in response to carer feedback. We worked closely with bereaved carers, and with staff from several NHS acute hospital trusts including the Heart of England NHS Foundation Trust and Guy’s and St Thomas’s NHS Foundation Trust. We are very grateful to everyone who has contributed to the project. All the quotes we have included are real quotes from carers. The project was funded and supported by the Transform Programme (*Transforming End of Life Care in Acute Hospitals Programme*), part of NHS Improving Quality.

There is a companion booklet, *Caring for carers*, aimed at hospital staff who may come into contact with patients who are dying, and with their families.

*The carer-friendly hospital: a good practice guide to involving and supporting carers in end of life care in acute hospitals* which will also be published in 2014. This detailed guide is aimed at decision-makers in hospital trusts.

Please send us your feedback! We would be grateful to hear your comments on this booklet. Please go to www.ncpc.org.uk/carers or email enquiries@ncpc.org.uk - thank you.

This booklet was compiled and written by Lucy Whitman, Involvement Officer, NCPC. Many thanks to everyone who contributed to the project.
This booklet is for anyone who is supporting an adult patient – a relative, partner or friend – who has been admitted to hospital and who may not have long to live.

Local information and advice for carers is available from:

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.