Caring for Carers

How to involve and support the family and friends of patients who are approaching the end of their lives in hospital

At all times the staff included me in the conversations, kept me informed, and treated me as part of Mum’s care team.

Do you work in a hospital? Do you come into contact with patients who are dying or who are nearing the end of their life, and with their families? If so, read on...

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

Improving Quality

NHS
Who is this booklet for?

This booklet is for any member of staff working in a hospital who may come into contact with adult patients who are dying, or are approaching the end of life, and with the carers of these patients.

Who are carers?

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.
The death of a family member or friend is a momentous event, and carers, as well as patients, need to be treated with compassion, dignity and respect at this critical time.

Carers are ‘expert partners’ who have much to give the dying patient, and much to offer to the professional team. The significance of their relationship with the patient needs to be acknowledged and honoured, and carers need to be included, involved and supported, both before and after the patient dies.

When carers are fully included and offered the chance to stay involved, the care provided by acute hospitals to people who are dying can be greatly enhanced, and the experiences of the person who is dying, their family and friends and the hospital staff can all be improved.

**Introduction**

She’s your patient — but she’s my Mum.

The family, including children, close friends and informal carers of people approaching the end of life, have a vital role in the provision of care. They need to be closely involved in decision making, with the recognition that they also have their own needs.

*(National End of Life Care Strategy 2008)*

Above all, what carers want and need, both for the patient and for themselves, is a truly personal approach.
Welcome carers as expert partners in the care of the patient.

Identify and acknowledge carers. Don’t make assumptions about relationships. Families and support networks come in all shapes and sizes and someone’s ‘next of kin’ may not be the person you expect.

A child or teenager may be the primary carer for a parent or relative, and their important role also needs to be recognised. Young carers need specialist support.$^1$

If possible, ask the patient, ‘Who are the important people in your life? Are you happy for us to share information with them about your condition?’

Address and refer to carers and patients by name. Find out what name they like to use (not everyone likes to be addressed by their first name).

Top Tip: Don’t talk to colleagues about ‘Bed 10’ – use the patient’s name
Carers have often been looking after the patient on a daily basis for some time and know much more about them than a nurse or doctor who has just met them.

Carers usually have a lot of valuable information about the patient. They can tell you what regular medication they are on, whether they have other conditions or health concerns in addition to the problem which brought them into hospital, their likes and dislikes, and any special support they need, such as sign language, or help with eating and drinking.

If a patient has any kind of communication difficulties, perhaps because of a stroke, dementia or a learning disability, it is even more important to listen to what the carer can tell you about them. The carer is used to communicating with this patient and may be able to interpret and/or give you some communication tips.

If a patient does not understand or speak English very well, the carer may be able to interpret occasionally on an informal basis, but it is good practice to provide a professional interpreter, to ensure that both patient and carer get an accurate understanding of the situation, and so as not to burden the carer with extra responsibility.

Don’t forget that young carers may also have important information to share about their relative, and they should be listened to and not sidelined. However, a carer under the age of 18 should not be asked to act as an interpreter; in this case a professional interpreter must always be provided.

**Top Tip:** Use a ‘This is me’ type booklet²
…about the patient’s treatment and care

Carers often have an overview of the patient’s condition which some of the hospital team may lack, especially if the patient has more than one illness, such as cancer and dementia.

If you listen to concerns raised by carers at the time, you may avoid a situation escalating, and a formal complaint being made.

Bereaved carers may be at increased risk of depression and ill health if they believe that their relative did not experience the best care before they died, and that no one listened to or acted on their concerns.
Listen to carers’ views...

...on the care and treatment the patient is receiving or has received

- Give people the chance to give feedback on the spot, in real time. This could be a daily ‘carers’ diary’, or a few questions on a postcard or an interactive screen.
- Remember that not everyone is confident about writing. Also ask people to tell you verbally if they are satisfied with the care.
- Send out a survey to bereaved carers.
- Invite patients and carers to take part in focus groups.
- Invite patients and carers to speak about their experiences at staff training sessions.
- Make sure there are patient and carer representatives on the Trust board.

Top Tip: Take action based on the feedback you receive!

Don’t be afraid to ask patients and carers for their opinions, and to share these views with your colleagues. You may receive lots of compliments which will boost staff morale. If there are any criticisms, you can discuss as a team how to put things right.

On the ward the staff made sure that Mum was comfortable and the care was first class. As a former nurse, I can’t fault it in any way. What made the five days bearable was the compassionate care shown to me by all the staff.
Staff are sometimes unsure as to whether they can share information about the patient’s condition with their carers, if the patient has not given their express consent.

If a patient wishes to withhold information from family and friends, and exclude them from decisions, these wishes must be respected by professional staff. In many cases however, the patient will have no objection to their carers being informed and involved.

**Top Tip:** If possible, ask the patient ‘Are you happy for us to share information about your condition and discuss your treatment with a nominated family member or friend?’ Record this information on the patient’s notes.

Patients who are close to death are often unable to take part in a conversation. If the patient is unable to communicate, or lacks capacity to give or refuse consent, the decision to share information with carers must be based on the best interests of the patient, and information should not be withheld without good reason.

A seventh principle has recently been added to the ‘Caldicott Principles’, which provide guidance to health and social care professionals on patient confidentiality.

**Principle 7:** The duty to share information can be as important as the duty to protect patient confidentiality. Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these Principles.

(Information: to share or not to share. The Information Governance Review, DoH, 2013)
**Talk to carers**

Give carers information and explain what is going on.

Carers say they want honest, clear, sensitive information about the patient’s condition and what is likely to happen. If the medical team think the patient is likely to die, most carers want to know this, so they can feel more in control and can use the remaining time well.

Carers say doctors and nurses often avoid talking about death or use medical terms that may not be understood.

At no point did anyone say that our son was dying.

I wasn’t able to prepare, and it was a shock.

They told us that my husband had metastatic disease, but they didn’t explain what that was.

When you do have to break bad news, try to do it sensitively.

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’.

**Top Tip:**

Many health professionals find it helpful to have specific training on how to initiate ‘difficult conversations’ with patients and carers when the patient is approaching death.
Wherever possible, when a patient may be approaching the end of their life, it is important to include carers as well as patients in discussions and decisions about care and treatment.

**Top Tip:** Always check whether a patient has an advance care plan, advance statement or similar document, or has clearly indicated their preferences for treatment and care in some other way, including stating who should be involved in decisions about their care.
Make sure carers are able to stay close to a patient who is dying.

If possible, offer carers the chance to stay involved in the physical care of their relative or friend. Not all carers will wish to do so, but for some people, especially those who have been caring for someone for a long time, it is painful if all the care is taken out of their hands just before the person dies.

Most of the time I was by my husband’s bed, helping with the nursing and being allowed to continue to care and support him as I have done for many years. Above all I was with him at the end of his life.

Carers may also wish to be involved in caring for their relative’s body after the person has died (and in certain religions this is an important duty for relatives).
Seeing a relative or close friend very ill and approaching death is a tough experience for most people. Ask carers how they are coping and offer a sympathetic ear. Find out if the family wants spiritual support from the hospital chaplains.

Try to make it more comfortable for carers who are spending long periods of time by the bedside of a dying patient, offering refreshments, a comfortable chair or folding bed, washing facilities etc.

Support carers

Top Tip: If someone asks you how you are, most people automatically reply, ‘I’m fine.’ If you really want to know how a carer is feeling as their relative approaches death, ask them a second time.

Your Trust may have agreed certain concessions for carers of patients who are expected to die, for example, more flexible visiting arrangements, or a discount on parking fees. But do all the carers know about these concessions?
If patient is discharged and is likely to die at home, make sure the discharge takes place as quickly as possible. Explain to carers what to expect, what they need to do and how to get help if they need it. Discuss discharge arrangements with the family and make sure there is enough support for the patient and the family at home.

**Top Tip:** Create a carers’ information pack, explaining hospital procedures, including any special arrangements for carers of people near the end of life, and listing local services and organisations which support carers.

Nobody ever told us there was support for us as parents and carers.

**Top Tip:** Consider having a Carers’ Champion for each ward, or for each hospital site, who can proactively offer information and support to carers, and advocate for them if necessary.

The hospital carers’ support service was helpful, supportive and efficient. I went home from the hospital that night and had a good night’s sleep for the first time in a month.
...and continue to support them after the patient has died

After the patient has died, their close relatives and friends need to have their loss acknowledged. They may need emotional or spiritual support, as well as practical advice and information about how to register the death, arrange a funeral etc. They may be very worried about money, and need financial advice about benefits and grants they may be entitled to. If they have been caring for a long time, their own health may have suffered.

After Dad died no one asked how we were. We were just given a booklet entitled ‘Because we care’.

My mother’s possessions were returned to me in a black plastic binbag.

When my husband died, the nurses all gave me hugs afterwards, and could not do enough for me.

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.
We did not have the money to pay for the funeral. The advice worker at the Carers Centre helped me to get a grant towards the cost.

Make sure members of the team know which local services or organisations, either inside or outside the Trust, can provide this support to bereaved carers\(^3\). These could include the Trust bereavement officers, social workers, carers centres, bereavement organisations etc. You may need to encourage a bereaved carer to see their GP, if they have neglected their own health due to the intensity and stresses of their caring role.

**Top Tip:** Create an information pack (online and in hard copy) for bereaved relatives, explaining the legal procedures which the hospital and the family need to carry out, listing the tasks the bereaved carers need to do, and saying where they can get emotional and practical support and advice.

**Top Tip:** Bereavement officers should familiarise themselves with the cultural and religious requirements of local communities with regard to care after death.
1. What are we doing well in our Trust, to involve and support the relatives and friends of patients who are dying?

2. Whose responsibility is it to make sure that carers are involved and supported when their relative is admitted to hospital near the end of their life?

3. What are the advantages for patients of keeping carers involved?

4. What are the challenges for staff of keeping carers involved?

5. How can we make carers feel more welcome on the ward?

6. Do we give carers an opportunity to tell us what they know about the patient and their condition?

7. Do we check to see whether the patient and carers understand what is happening, and understand the information we have given them?

8. Do we make sure that (unless the patient has said no) carers are involved in discussing the care and treatment plan?

9. Do we invite carers to stay involved in the physical care of their relative if they wish to?

10. What can we do to make it more comfortable for carers to stay overnight when their relative is close to death?
11. What information is available to carers to explain hospital procedures and special concessions for relatives of patients who are dying?

12. What opportunities do we give carers to give feedback in real time about the treatment and care their relative is receiving, and how do we respond to this feedback?

13. What information is there for carers about the practical and emotional support which is available for them?

14. How do we make sure that if a patient is discharged home to die, the carers know what to expect, and there is enough support in place?

15. If a patient dies in hospital, or soon after discharge, do we explain or give carers a chance to ask questions about what has happened?

16. What support do we give to carers when their relative or friend has died in hospital?

17. Do we return personal possessions to the family in a thoughtful way when the patient has died in hospital?

18. How do we collect feedback from bereaved relatives of people who have died in hospital?

19. What opportunities are there for bereaved carers to get involved and help us to improve our services?

20. What additional support do we need, as staff in a busy hospital, to help us to involve and support carers more effectively?
References

1. See http://professionals.carers.org/young-carers. There are young carers’ projects in many parts of the country. Check to find out what support is available locally. www.youngcarer.com/young-carers-services

2. ‘This is me’ is a leaflet for families to fill in giving key information about the patient. It was designed for patients who have dementia but could be useful for any situation where the patient lacks capacity or is unable to communicate. It can be downloaded from the Alzheimer’s Society website: www.alzheimers.org.uk

3. See www.carers.org/help-directory/bereavement and www.carers.org/carers-services/find-your-local-service. For young carers who have been bereaved see www.rd4u.org.uk.

Other useful resources

For carers

NCPC has produced a booklet to give to carers who are looking after someone who is admitted to hospital at or near the end of their life: Caring to the end, NCPC and NHS Improving Quality, 2014.

For patients with dementia and their carers

The Triangle of Care for Dementia, jointly produced by the Royal College of Nursing and Carers’ Trust, sets out good practice for looking after patients with dementia in the acute hospital setting. www.rcn.org.uk/development/practice/dementia/triangle_of_care

Organisations providing information and support for carers

Carers Trust www.carers.org
Carers UK www.carersuk.org
Carers Direct www.nhs.uk/carersdirect
This booklet is for hospital staff who may come into contact with adult patients who are dying, and with the carers of these patients. This includes doctors, nurses and other professionals, healthcare assistants and ward clerks, as well as ancillary staff.

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.

Look out for the companion booklet: *Caring to the end* – a guide for carers supporting someone in hospital who is approaching the end of life

*The carer-friendly hospital: a good practice guide to involving and supporting carers in end of life care in acute hospitals* 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 any member of staff working in a hospital who may come into contact with adult patients who are dying, or are approaching the end of life, and with the carers of these patients.

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.