



# End of Life Care Toolkit

## CHOICE Project

Care Homes and hospitals Innovating Collaboratively  
to increase End of life care options

July 2013

## INTRODUCTION

**As a nurse or carer working with people in a care home, you make a very important contribution to the quality of their lives.**

You get to know the people in your care and their families and friends. You help with activities of daily living such as washing, dressing and meal-times. You offer people choices such as what they would like to wear, eat and how they spend their time. You work with other members of the team when people become ill or disabled. Very importantly, as you will often get to know the people in your care very well, you can act as an advocate making sure their opinions and wishes are known and listened to. Your role is essential in helping people to live as well as possible until they die.

You may have a good deal of experience of working with people who are ill or disabled and you may also have experience of people dying. Some of you will have less experience in this area. To prepare this toolkit, we had meetings with care and residential home staff and sent out questionnaires to find out what you wanted to know.

Thinking and talking about death and dying is not easy and it reminds us that we, and those we love, will also die. From the meetings and questionnaires, we learnt that you sometimes struggle to know when someone is dying and to decide what to do when someone asks about dying. We learnt also that you may not know who to ask or where to go when a person has pain or other symptoms that cause them discomfort and distress. We learnt that you wish to give of your best to deliver care that is compassionate and respects the dignity of the person towards the end of life.

A **toolkit** is a set of tools that can help people to do their work well. The tools can be a list of **principles**, a description of the **actions** needed to do good work, **examples** of good practice and **questions** that remind people of the things they need to keep in mind. All of this is relevant to end of life care. We recommend that you work through each of the five areas in this toolkit and go through the 'kit' on each page. You can do this alone but, if possible, work with members of your team. We recommend too that you revisit the toolkit regularly and learn from feedback from your colleagues, people in your care and their family members and friends.

The **five areas** and related questions are:

- **Clarity about 'end of life'** - How will I know if the person I am caring for is nearing the end of her/his life?
- **Communication** - How can I talk to people in my care and their families and friends about end of life care and their feelings and wishes?
- **Considering symptoms** - How can I make sure that the person I am caring for is comfortable?
- **Coordination of care** – Who do I work with and contact for advice and support when I am unsure how to respond?
- **Compassion and dignity** - How do I give compassionate end of life care?

## CLARITY ABOUT 'END OF LIFE'

### *How will I know if the person I am caring for is nearing the end of her/his life?*

Recognising when a person in your care is nearing the end of life is not always easy. In our meetings with staff, one colleague who works in a care home said:

*'I think it depends because maybe some of our team leaders that have had more training and have been around a lot longer would be okay but most of our care staff, I don't think would be able to kind of distinguish if somebody is going to be end of life or if they're not because their needs just increase. It's hard because how do you know? I don't know how you can explain to carers when someone's going to be end of life. It is difficult isn't it?'*

[CHOICE Project participant]

### *Principles*

- A person is recognised as moving towards the end of life when their illness or disability means that cure is not possible, their condition cannot be reversed and they may die within months, weeks, days or hours [See **Appendix 1** for additional definitions];
- The end of life care needs of all people in your care should be considered in advance and sensitively discussed with the patient and/or family, in order to ensure all of the resident's needs and wishes are met;
- End of life care involves attention to the total needs of the person, that is, taking into account their physical, emotional, psychological, social and spiritual needs;
- Good end of life care means doing everything possible to help people live well until they die and includes paying attention to the needs of families/ friends.

### *Actions*

- Ask yourself 'would I be surprised if this person in my care was to die in the next 12 months?' and discuss your answer with a trusted colleague;
- Talk with colleagues about an end of life care situation you were involved in – How did you know the person in your care was dying? Were there changes in their eating, drinking, breathing or mental state?
- Invite colleague and, if possible, people in your care, families and friends to tell you their views of 'good end of life care' in your home

### *Questions for reflection*

- Think about one example when you delivered good end of life care – what was good about it? How did you involve the person and her/his family and friends?
- Read about end of life care – Do you know where to find reading materials? See, for example, [http://www.cpa.org.uk/cpa/End\\_of\\_Life\\_Care\\_Strategy.pdf](http://www.cpa.org.uk/cpa/End_of_Life_Care_Strategy.pdf)

## COMMUNICATION

### *How can I talk to people in the home I work in, and their families and friends, about end of life care and their feelings and wishes?*

A member of staff in one care homes told us that carers have a special role in end of life conversations:

*'Carers should be asking these sort of personal questions because the carers are the ones who have the strongest bond with the residents. They spend the most time with them, that's their family for them. For the residents, the carers are their family, so I believe it's the carers who should be having these sorts of conversations with them because they'll feel most comfortable, the residents would feel most comfortable with the carers'*

[CHOICE Project participant]

### *Principles*

- Appreciate that communication involves giving and exchanging information and can be verbal and non-verbal involving a sender, recipient and a message. Non-verbal communication can be written or through body language such as eye contact (*see Appendix 2 for communication tips*);
- End of life communication involves sharing information about care options and may involve breaking bad news, for example, that cure is no longer possible;
- Barriers to communication may be due to lack of time and space for end of life conversations; lack of carer confidence and knowledge; lack of capacity of the person and cultural differences; and
- Good end of life communication enables carers to find out what is important to people and their families and friends, for example, their preferred manner and place of death and after-death arrangements.

### *Actions*

- Ask an experienced colleague if you can observe them as they talk with people and their families/friends about end of life care;
- Give people the opportunity to discuss end of life issues. Provide information sensitively and listen to ensure you know their wishes and respect their decisions as far as possible;
- If a person is unable to express their views, find out if the person has made an advance statement and/or discuss decisions with their family/ friends. Such decisions must be made in the person's 'best interests'.

### *Questions for reflection*

- Think about an end of life conversation – What helped you to do it well?
- Read about end of life communication – what are the 'top tips'? (See <http://www.mywhatever.com/cifwriter/library/70/4970.html>)

## CONSIDERING SYMPTOMS

### *How can I make sure that the person I am caring for is comfortable?*

In our meetings with care and nursing home staff, you told us that sometimes staff would like to send people in your care to hospital due to symptoms but this may not be the right thing to do:

*'We had a lady here, she's just passed away. They said they wanted to take her to hospital because she wasn't eating, wasn't drinking and she was dying and her daughter said to them "no I'd rather her not go to hospital, I'd rather her stay here because of all the people that she knows" and she died the next morning. Her daughter feels better because she never sent her to hospital with people she didn't know. People with dementia, they know the faces or the voices don't they?'*

[CHOICE Project participant]

### **Principles**

- The aim of care is to help the person you care for to be as comfortable as possible by relieving pain and other distressing symptoms.
- Good end of life care includes physical, psychological, social and spiritual support for the person and her/his family and friends. This is called a holistic approach to care [See [Appendix 3](#)].
- Consider other factors that may be causing symptoms including, underlying disease, other medical conditions and side effects of treatments.

### **Actions**

- Ask an experienced colleague to tell you what they know about end of life care planning and how it can help the end of life care delivered in your home;
- In discussion with your colleagues, identify each of the symptoms that may make a person uncomfortable at the end of life and in particular in the final days of life (for example, pain, secretions, anxiety, nausea, difficult breathing and vomiting) and say how confident you are at responding to these;
- Discuss with your home End of Life Care Lead, those symptoms you are not confident about and learn how to respond better.

### **Questions for reflection**

- Think of an example from your practice where you responded well to distressing symptoms in an end of life situation and ask: What were the symptoms? What did I do? Why did it work well?
- Read about good end of life care and ask: How could it help with symptom control in your care home? How can creating a care plan help you to ensure good end of life care?

## CO-ORDINATION OF CARE

### *Who do I work with and contact for advice and support when I am unsure how to respond?*

It is sometimes difficult to know what to do and who to contact when a person is nearing the end of life. A staff member told us of reactions when there is uncertainty:

*'Half the time we don't know who to contact. If the team leaders are phoning the GP because they're medically trained, we need someone to say well actually this person is coming to the end of life. We don't always know who to speak to so they can tell us "this is what you need to do", for example, 'do we need a DNR [do not resuscitate] decision?' and things like. We need to know who to phone for support and advice.'*

[CHOICE Project participant]

### *Principles*

- Good end of life care needs input from people in your care, their families and friends and from care home staff who know the person well;
- End of life care can be improved by working with district nurses, general practitioners, specialist palliative care teams (usually based in hospices or hospitals), community palliative care nurses, pharmacists, spiritual care teams and bereavement support services;
- Good end of life care needs to be timely with appropriate colleagues consulted to help you manage symptoms and promote comfort before a situation becomes an emergency.

### *Actions*

- Ask an experienced colleague to describe an example of good coordination of care in an end of life situation in your home;
- Work with colleagues to ensure the contact details of end of life care experts in your area are correct and updated regularly [*See Appendix 4 'Who do I need to contact?'*], stating what they have to offer your home and their contact details
- Ask for feedback from a trusted colleague next time you think a person in your care requires a visit from a palliative care specialist with the expertise needed to care for people towards the end of their life.

### *Questions for reflection*

- Think about someone you know who was dying and ask: What were their needs? Who is best placed to respond to each of these needs? And what is my expertise in end of life care?

Read about different end of life roles and ask: What does each have to offer the people in my care?

[www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_close\\_relation\\_roles.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_close_relation_roles.asp)

## COMPASSION AND DIGNITY

### *How do I give compassionate end of life care?*

Many wonderful examples of sensitive end of life care were shared during our meetings and there are also dilemmas for staff. One colleague said:

*'If we're able to provide the care for residents to stay in their homes, if this is their home and it has been their home for a while, obviously they have to be given the choice of whether they want to stay [rather than go to hospital]. I think it's nicer for someone to be able to be in their own home and die at home if that's what they want rather than us shipping them out because we think we can't care for them. But it's just having the right support in isn't it? Some team leaders are quite open with their decisions and say "no, actually this person, I'll stick by their wishes, they don't want to go to hospital. You have to come here".'*

[CHOICE Project participant]

### *Principles*

- Dignity is about how people feel, think and behave. It is about valuing ourselves and other people. In care and nursing homes, it means that you must put the person in care at the centre of everything you do;
- Compassion involves feeling for the suffering of another person and having a wish or commitment to reduce that suffering;
- Look after yourself – You need to ensure that you have good support in place to help you do your job well and keep you healthy and happy.

### *Actions*

- Continue to deliver the kind of sensitive end of life care you told us about, for example, making time and sitting with a person in your care, holding their hand and comforting them and their family and friends;
- Ask for feedback from trusted colleagues, people in your care and their family and friends about your end of life care and ask how you might improve further;
- Talk with your manager about building discussions into the handover period or making time to build your confidence and competence in end of life care;
- Find out about local bereavement services for people in your care, staff and families;
- Ensure support for self and colleagues through peer support and clinical supervision/reflection

### *Questions for reflection*

- Think about, list and discuss responses to the compassion and dignity questions [*See Appendix 5*];
- Read about end of life care in nursing and care homes and ask: what do I do well in end of life care? How might I improve further? What training do I need? (see <http://www.nursingtimes.net/nursing-practice/clinical-zones/end-of-life-and-palliative-care/end-of-life-care-in-nursing-and-care-homes/5053468.article>)

# Appendix 1

## Clarity about 'End of Life'

We use many terms when we are talking about end of life care. What do these terms mean?

### End of Life Care

'This is care which helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social spiritual and practical support' [Source: National Council for Palliative Care 2006]

### Palliative Care

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life – threatening illness, through the prevention and relief of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.'

[Source: World Health Organisation 2003].

### Terminal Care

'This is the care given in the terminal phase of a person's life or in the last days of life. The terminal phase is the period when day to day deterioration particularly of strength, appetite and awareness is occurring'. [Source: Palliative Network Guidelines 2011]

'The last days of life is the period of time when death is imminent and when the time before the anticipated death is being measured in days'. [Source: NICE quality standard for end of life care for adults 2012]

### How do I know when a person is approaching the end of their life?

We cannot be exact about when a person is going to die, but there are clues that indicate that a person is approaching the end of their life and this will help us to meet their needs. People may have an advanced progressive, incurable disease e.g. someone with a cancer that has spread with no further cancer treatment possible; end stage organ failure; someone with advanced heart failure; someone who is frail with several illnesses; someone with advanced dementia

### How do I know when someone is entering the last days of life?

This can be difficult and therefore should always involve team discussion; the team may involve other care staff, the GP, patient and family.

If a person has been identified as approaching the end of their life, as above, and are deteriorating as expected from their advanced disease with the following signs, they are probably entering the terminal phase.

Symptoms may include: profound weakness e.g. bedbound; a change in awareness e.g. sleeping most of the day / night; little or no food or fluid intake; difficulty swallowing tablets; or a change in breathing and colour. The team will always review these symptoms in case there are any reversible causes that may need to be addressed



## Appendix 2

### Communication at the end of life

Communication is very important and can help to make an end of life situation comfortable and reassuring or distressing, for all involved. To get it right, you need to remember some basic **skills** (listening, empathy and time) and **top tips** (ask, expand, acknowledge feelings and plan):

**Listening** and hearing what the people in your care and their family and friends are saying is the most important skill. It involves more than just hearing the words that people say. You need to try to understand what they are meaning and feeling. Are they, for example, worried about something? Have they understood information they were given? Do they have special requests regarding their end of life care? The needs of family and friends should also not be forgotten and need to be listened to.

**Empathy** is a key skill and this is often communicated non-verbally through facial expression, tone of voice and body movements. Empathy can also be done verbally. Empathy is a core skill and is very important when communicating with people at the end of life and their family and friends.

**Time** is also important giving time for people in your care and their family and friends to talk about their situation and what is going to happen. You need skill to make time and space to have private conversations respecting the dignity of all involved at, what can be, a very difficult time for them. Your sensitivity will make a positive difference.

### Top tips for communication

**Ask** the person in your care and their family member or friends to tell you about their understanding before giving information. Information should always be linked to the people's needs.

**Expand** - people in your care and their family members are likely to experience a range of feelings such as guilt, loss and sadness. You may feel uncertain about how to respond in these situations. One way to respond and to keep the conversation going is to discover more and to ask people to please '**tell me more**'. You can then use your listening skills to understand what is being said. The 'tell me more' tool can help you understand what the issue is about and you can then provide information and support as necessary.

**Acknowledge feelings** – people in your care and their family members and friends are likely to feel distressed following the breaking of bad news about end of life situations. Acknowledging their feelings is very important. You may find it helpful to say, for example, 'this must be really hard for you'.

**Plan** - an advanced care plan should be in place for the people in your care and needs to be communicated to carers so everyone knows what the person would want as far as possible. Find out as much as you can about this from your colleagues.

See also

[http://www.e-lfh.org.uk/projects/end-of-life-care-\(public-access\)](http://www.e-lfh.org.uk/projects/end-of-life-care-(public-access)) &

<http://www.stchristophers.org.uk/steps>

## Appendix 3

### Considering Symptoms

Caring for the whole person requires us to think about addressing the physical, emotional, social and spiritual needs of those we care for.

No symptom should ever be seen in isolation, for example, a physical disturbance may be an expression of a deeper spiritual concern.

#### Physical needs

Consider the need to relieve symptoms which may include pain, agitation, breathlessness, secretions, nausea and vomiting

Monitor and address the following:

- Personal hygiene
- Elimination needs
- Personal preferences
- Communication aids
- Pressure area care
- Mouth care
- Eating and drinking

#### Emotional

The following may be indicators of emotional need and requirement for support:

- fear,
- uncertainty,
- not feeling valued,
- feeling insecure,
- sad,
- loss,
- hopelessness,
- loneliness,
- lost

#### Social

The following may be indicators of social need and requirement for support:

- feeling of isolation,
- changed relationships,
- low self-esteem,
- loss of identity,
- changed and unfamiliar environment, feeling of uncertainty

#### Spiritual

The following may be indicators of spiritual need and requirement for support :

- loss of values,
- questioning beliefs,
- uncertainty surrounding religious needs and wishes,
- loss of meaning,
- dealing with grief and loss

## Appendix 4

### Co-ordination of Care

#### Who do I need to contact?

The person should always be at the centre of planning care during the end of life and planning such care should never be done on your own, there are many different resources that can help and support you and the person you are caring for.

These may include:

**Family members or the person nominated as next of kin** - these people may be able to help you to ensure that the person's wishes are addressed. Continue to be mindful that each of these people will need support and help as they support the person they love and care for move towards the end of life.

**General Practitioners** - The general practitioner has overall responsibility and manages all aspects of the person's medical needs. These are doctors are skilled in managing symptoms in advanced disease and at the end of life.

**Community palliative care teams** - Community palliative care nurses are usually based in the local hospices, and are sometimes referred to as hospice nurses. . They visit people in their place of care and provide specialist knowledge and practical advice and support to enable family and you the carers to provide best possible care.

**Chaplain** - Contact with local chaplaincy services will help you to meet the spiritual and religious needs of an individual. Religion and spirituality plays an important role in people's lives and in their death. It is important to find out the importance of this role. The spiritual and religious needs of a person are individual and it is important to establish their beliefs and needs.

**District Nurses** – Community nursing teams provide nursing care in people's homes. Their role includes the management of people who are dying and are they are able to provide practical support and management surrounding symptom control and end of life care.

**Local pharmacist** - Pharmacists provide advice and guidance surrounding medicine management. Contact with local chemists to discuss the prescribing and delivery of end of life drugs is important, to ensure people receive symptom control in a timely manner.

**Your care home team** – involve other members of your team in planning care including - managers, carers, cooks, cleaners, office staff and volunteers.

All referrals to these teams should be discussed if possible with the person and/or family member. Referral to many of these teams provide access to knowledge and skills surrounding symptom control, psychological and spiritual support for the individual and their family as the end of life approaches.

## Appendix 5

### Compassion and Dignity

#### Questions for reflection and group discussion:

- 1) Think of a time when you, or someone you know, were suffering or distressed and received compassionate care?
- 2) Describe the situation – What happened? How did you recognise this as compassionate care? Did the person respond by smiling? Did they listen carefully? Did they touch the person suffering? Did they sit down and take time to be with the person?
- 3) How can your home help you to deliver compassionate care? Talk with your colleagues and manager and agree how you can do this together.
- 4) Dignity relates to the way we value ourselves and other people – think of examples of how you value yourself? How do other people show that they value you? How might your care home show that staff are valued?
- 5) How does your care home environment show that it respects the dignity of people in your care? Do members of staff ensure that people in your care are always private and not exposed, for example? How could the dining room be more like a restaurant? How do you show that you respect the dignity of the people in your care?
- 6) How does your communication show that you respect the dignity of the people in your care? And of your colleagues? What do you say? What eye contact do you have with people? What is your tone of voice? How do you position your body?
- 7) Talk with your colleagues and make a list of the things you are doing well to deliver compassionate and dignifying end of life care.
- 8) Now list the things you would like to do to improve further and agree the actions needed to make this happen. Make one person responsible to take the actions forward and to discuss the actions with the team at least every month.

*“How people die remains in the memory of those who live on”*

Cicely Saunders

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