Connected
National communication skills training

E-learning for end of life care
Training for health and social care staff

NHS

National End of Life Care Programme
Improving end of life care

National End of Life Care Programme
Finding the Words

Communication Skills Work Book

RosettaLife

MaguireCommunication
Skills Training Unit

Introduction

The art of communication is critical in all areas of our lives, and even more so for people nearing the end of their lives and for those people supporting them.
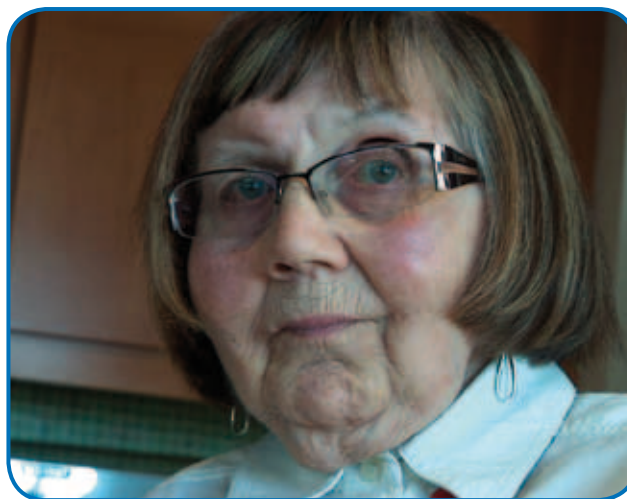
A group of people with life-limiting conditions, and those who have experienced the death of a loved person, came together to discuss their involvement with people who had the task of supporting those approaching the end of life. Through these discussions 'Finding the Words', the DVD and work book were developed to help staff in their conversations and care.

Communication extends far beyond the spoken word. Whether you are confronted with writing a letter, text, email, telephone call, using touch and making eye contact - your input will depend on your own self-esteem, confidence and experience as well as natural ability. Your thoughtfulness, skills and training will show themselves to those people with whom you are communicating, whether imparting an end-of-life diagnosis or supporting a person in the lifespan available. You may have only one opportunity to make a real difference and it is vital that, in your role as communicator, you feel that you have done your best. Be prepared!

Ann Macfarlane.

User consultant and advisor for the Communication Skills Pilot Project

Sections

This book is a resource for health and social care professionals whose work brings them into contact with people and families at the end of life. It accompanies the DVD **Finding the Words** and can be used individually or in small groups, with or without a facilitator/trainer, to help explore the issues discussed on the DVD and some of the evidence surrounding end of life conversations. Each section contains a quote from the DVD, a question to consider, a reflective exercise or some evidence to discuss.

Section 1: What do you want?

What are the things that matter most at the end of life?

Section 2: Communication Breakdown

How it feels when things go wrong.

Section 3: Cold Calls

When information is given without compassion.

Section 4: Am I a person or a disease?

The importance of seeing the whole person.

Section 5: Don't shoot the messenger

Reflections on how talking about dying affects health and social care professionals.

Section 6: How much truth can a spirit bear?

The importance of honesty.
What happens if we are not honest?
Giving significant information.

Section 1: What do you want?

"The first person who was asked was Neil and the first question he was asked was "What do you want?" and that to my mind is just the fundamental, the basic. Start from that premise and you can build up to good end of life care".

Question: What should we be asking people approaching the end of life?

> ## *Reflective exercise*
>
> **What things might be most important towards the end of life?**
>
> For the person approaching end of life?
>
> For relatives and carers?
>
> For you the health or social care professional?
>
> Why might people and carers find it difficult to tell us what matters to them?

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Key worries that people and carers might have at the end of life

Relationships	Am I still needed as a partner/parent/friend?	Existential/spiritual	Why me? Why now? What have I done to deserve this?
Physical/symptoms	Will I be in pain or experience any other physical symptoms such as incontinence, weight loss? Will I lose control of my bodily functions?	Psychological	Will it change how people view me? Will I be an outcast/avoided? Should I tell people? How? Will I lose control of my mind?
Treatment	Will it cause any unpleasant side effects? Will it prolong my life? Will I be able to cope?	Practical	What financial arrangements do I need? Who will look after the children, pets, parents, relatives?
Social/support	Who will look after me? What extra help is there?	Dying	How long? How ill will I become? What will it be like?

Section 2: Communication Breakdown

"Last week I was at my mum-in law's bedside from 4:30am on the Saturday morning until 8:30pm on the Tuesday evening and whilst the staff … did an excellent job of looking after my mother-in-law I have to say that communications between the staff was not good. I spent all of those 4 days behind curtains, closed curtains…. I'm sure they were oblivious to our needs".

Question: What prevents people from sharing worries and needs?

Fears	
	• being stigmatised
	• being judged ungrateful or inadequate
	• breaking down and crying
	• burdening health and social care staff
	• causing distress to others
	• not being able to find the words

Beliefs	
	• problems are an inevitable part of illness so health and social care staff should anticipate them
	• problems cannot be alleviated
	• professional people are only interested in certain types of problems
	• this is not the 'right' professional person to talk with
	• professional staff are too busy

Communication challenges	
	• it's hard to find the right words
	• the right questions weren't asked by the professional
	• problems hinted at but not picked up by the professionals
	• not communicating in first language
	• cognitive impairment

Question: Why do professional staff struggle to talk about dying?

The conversations I find most difficult are _____

_____

I find these conversations difficult because _____

_____

Barriers to communication

Fears

- unleashing strong emotions

- making things worse

- facing difficult questions

- taking up too much time

- facing our own failure

Beliefs

- emotional problems are inevitable and nothing can be done about them

- it's not my role to discuss such things

- there's no point talking about problems that cannot be solved

Lack of skills or confidence in

- starting end of life discussions

- exploring concerns

- handling difficult questions -saying the 'right thing'

- closing the conversation sensitively

Workplace

- lack of support from colleagues or managers
- lack of privacy
- time constraints
- noise/distractions
- nowhere to refer for psychological support
- no training or supervision in communication skills

Above are some examples of barriers to communication. How many do you recognise for yourself and in your workplace?

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Section 3: Cold Calls

"I was given a phone call … over the phone by the respiratory nurse to tell me "by the way, thought you'd better know, cause you're going to get a copy of the letter … you're actually end stage now".

Question: What would you want from the professional people around you if you needed a trustworthy person, or a person with whom you could talk or just 'be'?

Empathy is: The ability to recognise the felt experience of another person. To put oneself in their position and to see the world from their perspective.

Empathy is not: Feeling the same, or how you would feel in that situation.

Reflection: Some people would say that in order to feel compassion you first have to be able to empathise – to see the situation from the other person's point of view. What do you think?

Some ways in which we **stop** people from telling us about their concerns and needs:

Person says "I was upset about being ill"

Overt blocking
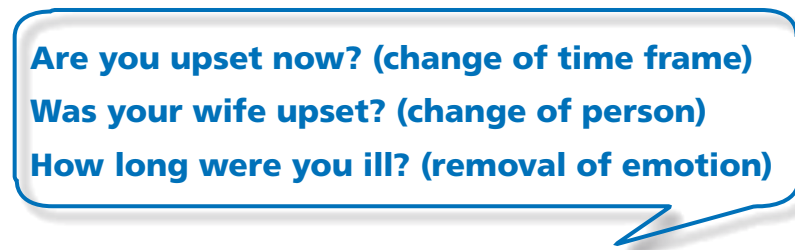- complete change of topic

Distancing
- more subtle change of focus

> **How's your family?**

> **Are you upset now? (change of time frame)**
> **Was your wife upset? (change of person)**
> **How long were you ill? (removal of emotion)**

Blocking - Questions! Questions!

Physical	Did you have a lot of symptoms?
Closed	Did you tell anyone?
Multiple	How are you, is the pain any better?
Leading	You'll feel better in a minute won't you?
Defending/justifying	I'm sure the doctor didn't mean to upset you
Premature reassurance	You'll feel better after you've seen the doctor
Premature advice	You need to….
Normalising	Everyone gets upset when they're ill
Minimising	It won't be as bad as you think
Jollying along	Come on you have to stay positive

Some questions to reflect on

Imagine you just received some really bad news and were devastated. How many of the above statements and questions would you want to hear? How do they make you feel? Why do you think we say these things? (There are no right or wrong answers)

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Section 4: Am I a person or a disease?

"I think sometimes we put the diagnosis or the treatment or the prognosis in front of the fact that we are actually dealing with a person. A person who has relationships with other people and… sometimes the objectives of the medical staff might not be the same as the objectives of the person"

"In about 3 of 4 weeks time, I've got to go under the surgeon's knife with a man who I've been battling with for ages to treat me as a person and not as a piece of… in this case as a rectum"

"We often meet up with professionals who do not realise that we have had lives, experiences and we are not treated as people with a past"

"No I really agree with that, it's as if our totality as people and our life experience is completely eroded… Disregarded"

Question: What do we mean by the term "person-centred"

Reflective exercise

On the next page is an excerpt from a well-known poem by Phyllis McCormack "The Crabbit Old Woman" which reflects some of the experiences shared in the DVD. Alongside it is a nurse's response.

Do you think lack of time is a reason for not seeing the whole person or an excuse?

How much do the barriers and challenges we discussed in Section 2, Communication Breakdown, get in the way of seeing the whole person?

Are there ways in which we could acknowledge and recognise the whole person?

What are they?

"Crabbit Old Woman"

What do you see, what do you see?
Are you thinking, when you look at me -
A crabbit old woman, not very wise,
Uncertain of habit, with far-away eyes,
Who dribbles her food and makes no reply
When you say in a loud voice,
I do wish you'd try.
Who seems not to notice the things that you do
And forever is loosing a stocking or shoe.
Who, unresisting or not; lets you do as you will
With bathing and feeding the long day is fill.
Is that what you're thinking,
Is that what you see?
Then open your eyes,
nurse, you're looking at me.

A nurse's response to "Crabbit Old Woman"

What do we see, you ask, what do we see?
Yes, we are thinking when looking at thee!
We may seem to be hard when we hurry and fuss,
But there's many of you, and too few of us.
We would like far more time to sit by you and talk,
To bath you and feed you and help you to walk.
To hear of your lives and the things you have done;
Your childhood, your husband, your daughter, your son.
But time is against us, there's too much to do –
Patients too many, and nurses too few.
We grieve when we see you so sad and alone,
With nobody near you, no friends of your own.
We feel all your pain, and know of your fear
That nobody cares now your end is so near.
But nurses are people with feelings as well,
And when we're together you'll often hear tell
Of the dearest old Gran in the very end bed,
And the lovely old Dad, and the things that he said,
We speak with compassion and love, and feel sad
When we think of your lives and the joy that you've had,
When the time has arrived for you to depart,
You leave us behind with an ache in our heart.
When you sleep the long sleep, no more worry or care,
There are other old people, and we must be there.
So please understand if we hurry and fuss –
There are many of you,
And so few of us.

Section 5: Don't shoot the messenger

"I've been wondering how people whose profession it is to give bad news, to talk about people, maybe give them the news their life is very short … how (do) they cope?".

Question: How do you cope with facing other people's distress?

Reflective exercise

"Special people" and you

As professional people, most of us can identify particular people who for one reason or another we became more attached to than usual or who have affected us deeply. Think of a particular person with whom you have worked. Perhaps there was something very special about him or her. Perhaps something about the circumstances that reminded you of your own. Perhaps the illness or death was especially tragic or traumatic.

What was it about this person that affected you?

How did you cope? (What helped? What hindered?)

What else did you need? (From colleagues, from managers)

What have you learned from this that will support you in the future?

Listening *is* communicating

In Section 2 we discussed behaviours that block communication. Below are some skills that help people to share their concerns and feel heard and understood. Communicating well makes us more effective and can reduce our own feelings of stress and helplessness.

Skill	Communicates
Eye contact and attention	"you are important"
Minimal prompts: "yes, go on"	"I'm still listening"
Acknowledging/reflection: "you had a rotten time by the sound of it" "you look/sound upset"	"how you feel matters" "I can see you're upset, it's OK to tell me about it and I want to help"
Paraphrasing: "being ill has been really distressing"	"I want you to know I've heard you and also to check that I've got it right"
Open question: "How are you feeling?"	"I'm interested/concerned"
Open directive questions: "What's most important to you right now?" "How did it feel when you heard…?"	"I think you might have concerns or needs and I want to help"
Educated guesses: "I imagine that news came as quite a shock"	"I have an idea about how you may be feeling. Do you want to tell me?"
Negotiation: "are you able to say what is worrying you"	"I'm willing to listen but I can see it's hard and I don't want to pry"
Clarifying: "what were the things about being ill that upset you?"	"I'd like to understand exactly what the problem is?"
Summarising: "so what's most important is…" (list what was said)	"I've heard you, have I got it right, have I missed anything?"

Section 6: How much truth can a spirit bear?

" …right from the very beginning I went out and researched everything I could to find out about prostate cancer…Now some of us are like that…others are not. Others, and I can assure you from the work I've done in support groups and counselling work, some want to do that…(faces away)…They do not want to see the 'nasties' "

Question: What do you think are the consequences of giving people too much, too little or inappropriate information?

But I don't give bad news do I?

I'm really sorry but….

We haven't been able to get the care package together in time to get you home today

He's going to have to go into hospital

We're worried about the symptoms

Your wife's not so well today

Bad news is <u>any information</u> which may impact on the person or carer's view of the future

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So how much truth can you dare?

"And I honestly believe that if somebody had been honest with us at an earlier stage and said "go for the quality of life now. Enjoy and accept the fact that it's going to be short" it would have been so beneficial. As it is, we're left with these feelings, "if only we had….""

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Question: How can we find out what people want to know?

Reflective exercise

The experiences in this section show what these particular people and their carers wanted.

Do you think all people want to know the same things?

Do you think that what people want, changes over time?

How often do you have to break bad news? (If you think you don't break bad news look at the previous page and ask yourself again!)

Giving significant information

Information and advice is more likely to be both heard and absorbed if it is delivered in manageable chunks tailored to the needs of the individual **AND** allows the resultant concerns and feelings to be acknowledged

1. **Check awareness of the situation and explore the reasons.**
   "Before we start talking about plans for the future can I just check how you are seeing the situation at the moment?"

2. **If they are aware that the person is dying.**
   Give a warning shot and confirm their understanding *"Unfortunately, I think you are right, your mum is dying"* (Move on to 7.)

3. **If the person is not aware.**
   Give a warning shot. *"I'm afraid she doesn't seem so well today".*

4. **Pause to let that sink in.**

5. **Continue to explain in small steps**, using the responses to guide both your speed and the size of the steps:

   Carer   *"What do you mean not so well?"*

   Professional *"Well we're quite concerned about her"*

   Carer   *"Oh dear … why?"*

   Professional *"OK. We were hoping the antibiotics might help to relieve her chest infection"*

   Carer   *"Yes"*

Professional	*"But unfortunately they haven't worked"*
Carer	*"That sounds bad … so what can you do?"*
Professional	*"I'm afraid we can't relieve her chest infection"*
Carer	*"So what does that mean … does it mean … oh dear"*
Professional	*"What exactly are you asking me?"*
Carer	*"Does this mean the end?"*
Professional	*"I'm afraid it does yes"*
PAUSE	
Professional	*"I'm very sorry to have had to tell you that Mr Jones"*

6. **If a person indicates** that he or she does not want to know more. Tentatively acknowledge and explore the reasons why. Double check the level of information they do want. If they still don't wish to know more – suggest meeting again later.

Once Bad News has been broken:

7. **PAUSE to allow it all to sink in.**

8. **Avoid** moving into advice or reassurance mode. (Refer back to the facilitative skills on page 13)

9. **Empathise and acknowledge feelings** (shock, distress, etc) and ask if willing to share their feelings.

   "I can see what I have said has left you very upset. Can I ask you how you are feeling about all this?"

   "I know this seems a stupid question right now, but how are you feeling?"

10. **Help person/carer identify resulting concerns**, worries, fears and information needs.

11. **Discuss each concern** in turn with a view to action where possible.

12. **Help person prioritise** these concerns.

   "What is most important to you right now?"

13. **Give required information** and treatment details tailored to the person's concerns.

Finally:
Check out how the person is left feeling before closing the conversation.

The last word

This workbook was inspired by the experiences of the contributors to the DVD Finding the Words, who wanted to help health and social care professionals understand what mattered most to them and their families towards the end of life. The last word should be theirs.

"The staff on the ward whether it's cleaners or consultants - it's their patch, it's their territory and the people who flow through the wards are only temporarily there. And yet, for each of those patients and their families and their carers, they are the most important person there at the time."

"It is that understanding, those little important things, and I suppose that's a message I really want to get across, it's not the big things that matter so much it's the very small things that are very ordinary."

Useful Resources

- See the communication skills pages on the National End of Life Care Programme's website:

  http://www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills

- There are over 150 highly interactive sessions of e-learning within e-ELCA which are freely accessible to health and social care staff:

  http://www.e-lfh.org.uk/projects/e-elca/index.html

- Difficult Conversations for people with COPD available from National Council for Palliative Care

  http://www.ncpc.org.uk/library

- Talking Mats-resources to support people with communication difficulties:

  http://www.talkingmats.com/

- Social Care Institute for Excellence (SCIE) Video on supporting people with dementia at the end-of-life.

  http://www.scie.org.uk/socialcaretv/video-player.asp?guid=6cddd9aa-041e-446e-b637-d47ab7b37643

- Information leaflets and resources available to support people to talk about their wishes towards the end of their lives are available from the Dying Matters website:

  http://www.dyingmatters.org/

Notes