

# Caring for adults



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# Introduction and guidance

## Introduction and guidance

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*Caring for adults* is an introductory course for both paid and unpaid carers who are supporting people at home or in a residential, community or day care setting.

Whether you are in a paid or a voluntary caring role, or caring for a family member, this course will help to extend your knowledge and skills to develop your awareness of a range of topics: interpersonal skills for care, mental health problems, dealing with emergencies and looking after yourself as a carer. The course also considers the difference between supporting other people with their basic daily needs and more involved care responsibilities that will also depend on the needs of the cared-for person.

Each section of the course offers short, interactive quizzes to test your knowledge.

Successful completion of the course will enable you to achieve an online badge and a statement of participation. This course does not carry any formal academic credit.

However, it does provide a way to help you progress from informal to formal learning.

## Guidance for accessing alternative formats

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You can download this section of the course to study offline. The alternative formats offered that will best support offline study include Word, PDF and ebook/Kindle versions of the materials. The other alternative formats (SCORM, RSS, IMS, HTML and XML) are useful to those who want to export the course to host on another learning management system.

Although you can use the alternative formats offline for your own convenience, you do need to work through the online version of the course for full functionality (such as accessing links, using the audio and video materials, and completing the quizzes). Please use the downloads as convenient tools for studying the materials when away from the internet and return to the online version to ensure you can complete all activities that lead to earning the badge.

In order to access full functionality in the online course, we recommend that you use the latest internet browsers, such as Internet Explorer 9 and above and Google Chrome version 49 and above.

If you have difficulties in streaming the audio-visual content, please make use of the available transcripts.

## Structure of the course

This course has five sections, with each section focusing on a particular aspect of caring for adults:

1. **[Good communication](#)** looks at ways of communicating, improving your listening and interpersonal skills, and recording and reporting.
2. **[Mental health awareness](#)** considers types of mental health problems and how they affect the cared-for person and the role of the carer.
3. **[Palliative and end-of-life care](#)** examines how care is provided for people who receive palliative and end-of-life care, and what is meant by a good death.
4. **[Positive risk-taking](#)** explains why it is important to balance safe care with positive risk-taking to promote a more fulfilling life for the cared-for person.
5. **[Looking after yourself](#)** looks at the importance of carers looking after their own physical and emotional well-being and ways to manage stress.

Together they amount to approximately 15 hours of study time. Each section has a mixture of reading, video clips, activities and quizzes that will help you to engage with the course content.

A further section, **[Taking my learning further](#)**, will enable you to reflect upon what you have learned within this course. It also directs you to relevant websites and resources, which further relate to the development of your learning and career prospects.

Once you have studied a section, you will be asked to complete a short online quiz of no more than five questions per section. This helps to test and embed your learning.

*Caring for adults* is designed to allow you to dip in and out of the resources, so that you can study in small chunks to fit around your work and life commitments. If you choose to complete all sections of *Caring for adults* and collect the badge, you can download a statement of participation that recognises your achievement. You may find this useful to show your employer as evidence of your learning. For more information on how to obtain your badge, read [What is a badge?](#)

## Navigating the website

To find your way around this course, you simply click on the links. The home page has links to all the sections, quizzes and relevant resources. When you are in a section, the left-hand menu has links to that section's topics and its associated quiz. The menu also has links to the other sections of *Caring for adults* and to the resources section.

If you feel unsure, practise hovering your mouse over a link in the menu and clicking on it. This is the easiest way to move from page to page. You can also click on the 'Next: ...' link at the end of each page of text. Don't worry about breaking a link or damaging the web page – you won't. Have a go as soon as you can before you begin your study.



## Why study this course?

John Rowe, one of the authors of this course, will now give you a bit of background into why you might like to study this course.

Video content is not available in this format.

Welcome and introduction from the author



If you are already a carer, you will find it helpful to consider how your role and experience matches the topics covered in the course. The guided activities throughout this course will help you to learn and reflect on your own role. If you are in a paid carer role, completion of *Caring for adults* will allow you to demonstrate to your employer your understanding of what it is like to be a carer. Your employer might also ask you to study this course as part of your induction into a new role, or for your professional development.

Although this course is primarily for carers, it also considers some issues experienced by both carers and cared-for people, for example stress, tiredness, depression and anxiety. We have therefore devoted Section 5 to looking after your own health and well-being, with much of the advice also applicable to the people you care for.



## Learning outcomes

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After completing this course, you will be able to:

- describe the role and responsibilities of carers
- recognise some of the basic concepts that will enable a person-centred approach to care
- identify the different needs of a cared-for person, at different stages of their care
- understand the impact that caring may have upon carers, and how this might be managed
- explain some of the legal responsibilities within the caring role.

# Before you begin

Spend a few moments thinking about your current learning needs and opportunities by doing Activity 1 below.

## Activity 1

Allow about 15 minutes

Below is a link to a short questionnaire to get you thinking about:

- What are your current priorities for learning?
- How does studying a short online course fit into your everyday lifestyle?
- What goals are you hoping to achieve by studying this course?

[Questionnaire about your learning \(1\)](#)

Hopefully, by the end of the course you will be able to reflect on your answers.

We hope you enjoy the course!



# Good communication

## Introduction

---

In this section about communicating well, you will look at the different ways in which we communicate, whether we are aware of it or not. Communication is something we all do, but if you are caring for someone, either paid or unpaid, the way you communicate can have a significant impact on your relationship with that person. You will be checking your interpersonal skills and your ability to listen fully and with empathy. (Empathy is the ability to identify with and understand somebody else's feelings or difficulties.) The next thing you will look at is how you can help the people you support to communicate more effectively, and your written communication in particular. So you will be considering the place recording and reporting have in the care you offer.

At the end of the section there is a short quiz to test how much you have learned about communicating well. On successful completion of the quiz you will earn a digital badge.

The section is divided into five topics and each of these should take you around half an hour to study and complete. The topics are as follows:

1. **What is communication?** looks at the ways and reasons people communicate, the barriers to communication and ways to overcome them.
2. **Developing your interpersonal skills** explores interpersonal skills and the way we use them in all areas of our lives. It also looks at ways to develop those skills, including becoming a better listener and working as part of a team.
3. **Are you listening or waiting to speak?** examines the importance of being able to listen, and looks in further depth at the different levels of listening and how and when to use them.
4. **Ways to help people communicate** discusses ways to become a better communicator, including ways to communicate with people with dementia and learning disabilities.
5. **Recording and reporting** outlines the reasons for being clear and specific in written records and reporting situations, and gives guidance on how best to complete documentation of this nature.

## Learning Outcomes

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By completing this section and the associated quiz, you will:

- understand the importance of good communication and the different ways of communicating, including the role of active listening
- understand ways of developing good interpersonal skills and the importance of accurate and factual record-keeping.

# 1 What is communication?

## Activity 1

Allow about 10 minutes

Have a look at these images. What do all these things have in common?



(d) Cat winding itself around its owner's feet and purring loudly



(h) A TV with the news coming on

Figure 1 What do they have in common?

Look again, and make a note of what you think each of them is communicating.

(a) (b) (c) (d) (e) (f) (g) (h)

## Discussion

- Bird singing – could be trying to defend its territory or attract a mate.
- Ambulance with flashing lights and siren – get out of the way, I'm in a hurry.
- Phone with incoming text message – someone wants to ask or tell another person something.
- Cat winding itself around its owner's feet and purring loudly – this usually means that it wants its dinner!
- Person holding another's hand – offering comfort or kindness.
- Baby crying – its only way to tell you that something is wrong.
- Phone ringing and person answering – someone wants to ask or tell another person something.
- Radio/TV with news coming on – information about what's going on in the world.

They are all communicating in some way – they all have something to tell you.

We communicate all the time, sometimes without realising it. Something as simple as a raise of the eyebrow, a smile or a frown can convey a clearly understood message from one person to another. In fact, everything we do is communication. We can show people what mood we are in just by the way we walk down the street or by the way we answer the phone. The next activity asks you to think about the ways people communicate.

## Activity 2

Allow about 5 minutes

As you just saw, there are many ways to communicate. See if you can write down at least ten of them here.

*Provide your answer...*

## Discussion

Here are just some of them:

- blog
- body language
- email
- eye contact
- Facebook
- letters
- physical gestures
- pictures
- podcast
- radio
- sign language
- Skype
- speech
- telephone
- text
- touch
- TV
- Twitter
- voice-simulator

and many more.

## 1.1 Barriers to communication

Good communication is vital in social care. It enables us to build relationships with the people we care for and their families, develop relationships with people we work with and other professionals, provide clear information and carry out appropriate reporting and recording.

From the time we get up to the time we go to sleep, we are communicating. We can have hundreds of moments in a day when we are communicating in many different ways, and with many people. But not everyone is that fortunate.

Some people have real difficulties with communicating what they want from us, and this can sometimes lead to behaviour that we find hard to deal with due to their frustration at not being able to make themselves understood and get their needs met.

When we communicate, it's not just about the actual words we use (verbal communication). We also need to think about the way we say those words – our tone of voice, the speed of our words, how loudly or softly we are speaking (vocal communication) and what our bodies – especially our faces and hands – are saying. This body language is called visual communication and it includes the way we stand or move our bodies, the way we use our hands, the expression on our faces and the eye contact we make.

### Activity 3

Allow about 15 minutes

Watch this video:

View at: [youtube:2JsiWJpKPqc](https://www.youtube.com/watch?v=2JsiWJpKPqc)  
If waiters were honest

If you didn't understand the words these people were saying, what impression would you get of the service you were receiving?

Think about what the people in the video were telling you:

- the words they use
- the way they say the words
- their body language.

Which of these did you notice most? Write your thoughts in the box below.

*Provide your answer...*

### Discussion

It is easy to see from the video that the words we use are only a part of the message we are communicating when we speak. The speech of the people in this video says something entirely different from what they are saying with their tone of voice and body language. Think about this when you are with the people you care for, and consider what message you are giving to them, especially if they can't understand what you are saying.

## Visual, verbal and vocal communication

You are now going to think about visual, verbal and vocal communication, and which of these types of communication we use most often.



### Activity 4

Allow about 2 minutes

What percentage of our communication is verbal, vocal or visual, do you think?

- |   |           |            |
|---|-----------|------------|
| <input type="checkbox"/> (a) Visual 43% | Vocal 21% | Verbal 36% |
| <input type="checkbox"/> (b) Visual 71% | Vocal 2%  | Verbal 27% |
| <input type="checkbox"/> (c) Visual 55% | Vocal 38% | Verbal 7%  |

#### Discussion

(c) Visual 55%      Vocal 38%      Verbal 7%

## 1.2 How do things go wrong?

There are lots of ways in which things can go wrong with verbal communication. Listed below are just a few of them.

- Maybe the person doesn't understand what you mean.
- They may misinterpret what you have said.
- They don't hear correctly.
- You may have given too many instructions at once.
- You chose the wrong time or place to have a difficult conversation.
- The information may have been confusing.
- The other person may not speak the same language as you.

Have you ever had to deal with some of the situations shown in Figure 2?



(a) Everybody talking at once



(b) Trying to reason with someone who doesn't want to listen to you



(c) Talking to someone whose attention is elsewhere (e.g. texting or fiddling with things)



(d) Someone who won't turn around to look at you while you are talking



(e) Trying to understand someone with no verbal communication



(f) People rolling their eyes or sighing/tutting when you ask them for something, even though they do what you ask

#### Figure 2 How verbal communication can go wrong

We give messages we aren't aware of with our body language, especially if the other person has limited understanding of the language being spoken. So you need to take extra care to choose the right time and place, and to give people time to process information. If you keep repeating things because someone with limited understanding hasn't responded quickly, the process often has to start again.

In the next activity you will see how confusion can arise if our words do not always match the other messages we are giving with our body language and facial expressions.

#### Activity 5

Allow about 10 minutes

Read the case study and then answer the questions that follow.

#### Case study: Rosie

Rosie lives in a supported living unit with five other people with learning disabilities. They are supported by a team of staff. Rosie is able to verbally communicate her needs and emotions clearly, but some staff see her as being very demanding and are not always happy to work with her.

Verbally the staff are always pleasant to Rosie, saying all the right things. But their non-verbal communication gives a different message. For example, Rosie asks for her third drink of the morning. Pam, who is trying to watch a programme on television, says 'Yes, sure Rosie, coming right up' but when she says it, she sighs and rolls her eyes. She brings back Rosie's tea and smiles, puts it down muttering 'What did your last slave die of?' and walks away, without waiting for any further comment from Rosie.

- If you were Rosie, how would you feel about this incident, and why?
- If you were another member of the team, what would you say to Pam?

*Provide your answer...*

### Discussion

Rosie probably feels that Pam doesn't like her very much because she has seen Pam's facial expressions and heard her muttered comments. She is confused because Pam is still smiling and getting her what she asks for.

Another member of the team might speak to Pam because her treatment of Rosie is unfair. If Pam thinks Rosie is being demanding, Pam needs to discuss this with the rest of the team and they should agree on coping strategies for those staff who find Rosie difficult to deal with.

It is all too easy to get into bad habits when it comes to communicating, as the next activity will show you.

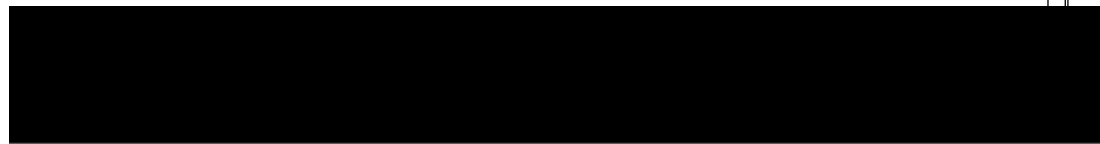
### Activity 6

Allow about 10 minutes

Look at the following video and think about the way these staff members are behaving, and how it could be done differently.

Video content is not available in this format.

Bit of sugar, love?



### Scenario Two

"bit of sugar love?"



Working in an empowering way – bit of sugar love

- Write down three things you would do differently.

*Provide your answer...*

### Discussion

The staff are having a conversation over the cared-for person rather than involving him in the conversation. They are also not focusing on their task, which is to help him with his breakfast. They should have focused on ensuring that he was able to reach his drink. When supporting him with his food, the staff should ask how he prefers his food and wait for his response, and ensure that he is happy with the way the food is given to him.

You may want to take some time outside of this course to consider when your communication has been misunderstood, and what steps you could have taken to eliminate misunderstanding.

## 2 Developing your interpersonal skills

In your role of supporting others you will often need to communicate with the people you support, as well as with the other people involved in caring for that person.

If you care for someone at home, you may need to speak to social workers or medical professionals, as well as friends, family and neighbours in order to get the right support for that person and for yourself. It is important to make the most of these opportunities, and to do that you may need to develop your interpersonal skills.

### 2.1 What are interpersonal skills?

We use our interpersonal skills to communicate and interact with people. Having good interpersonal skills can often result in us having positive relationships with our family, friends and work colleagues especially. We use our interpersonal skills in everything we do. However, these skills are not something we are taught in a classroom. We usually learn them in daily life by seeing others use them with positive results.

Here are some examples of interpersonal skills:

- the ability to express yourself clearly and confidently
- being aware of body language and facial expressions
- listening to others completely and with empathy
- being willing to collaborate and work as a team
- understanding implied rules of behaviour
- being able to assert yourself without making the other person seem small or you to appear angry and aggressive
- being responsible and timely
- being able to speak for, or support, others who are less able to do it for themselves (advocacy).

It takes time and practice to develop good communication and interpersonal skills. The more you interact with other people and the more you are exposed to a wide range of experiences, the more likely you are to develop these important qualities. One of the most important interpersonal skills you need in your role as a carer is being able to collaborate and work as a member of a team. Often the people you are caring for will have support from a wide range of people and agencies, and good communication is key to being part of a team that works well.

In the next activity you are going to be thinking about the people who make up teams, and how those teams work. You will also have the opportunity to reflect on your own experiences of being part of a team.

#### Activity 7

Allow about 10 minutes

Marie is a paid carer, who works for an agency. Read her story and then answer the questions that follow.

## Case study: Marie

I have been really busy since I started working for the agency. I have done a lot of work with Leonard Cheshire as a home carer. I feel that I have established a good reputation for reliability as I never like to let my clients down. My kids are quite happy to look after themselves before and after school and they are old enough to leave safely. I think they would like me to be around a bit more, but I tell them that if they want the extras they have to put up with doing more around the house and eating ready meals. They don't really mind because they can choose what they eat!

The manager of the agency says that I am one of her best workers and lots of my regulars know me now and ask after me if I'm not there. She knows I'd prefer permanent work, but the agency pays more, otherwise I'd work for Leonard Cheshire permanently.

One of the best things about being agency staff is you don't get involved in all the office politics and I find some of the other carers can be very spiteful, especially about us agency people. They think we don't work as hard as they do, or that we don't care about the people we are looking after.

It's hard to find time to get to know other people and they all seem to have friends already, so maybe they don't want to mix with agency people – I don't know. I sometimes feel like they resent me because I am paid more than them for the same work, but I tell them they could leave and work for the agency as well. I don't understand why they don't if the money is so important.

Now see if you can list all the teams that Marie is part of, and say what her role is in each team.

- What advice could you give Marie about working in each team?
- Have you worked as part of a team? Was it a successful team? If so, what made it work well?
- If it was not successful, can you think of why it did not work well?

*Provide your answer...*

## Discussion

This is a useful activity for reviewing your understanding of the ideas in this section about interpersonal skills.

Marie is part of three teams: the agency, Leonard Cheshire and her family.

In her agency team Marie is part of a support network for other services.

In her Leonard Cheshire team, Marie must be flexible, filling whatever role she has been asked to fill, but she does not belong to the wider team, as they see her as an 'outsider'.

In her family team, Marie takes on the role of team leader, and allocates tasks to other members of the team (her children) and expects them to be fulfilled.

Advice about working in each team

Marie could develop a better understanding of the agency team that she is part of, and how that supports other teams, such as Leonard Cheshire.

Alternatively, she could start to gain a better understanding of the relationships in the group where she spends a lot of time (the Leonard Cheshire team) and where she fits into this.

Marie might also look at the change in roles in her family now that she is working longer hours, and whether her children feel they are part of a team.

For your own reflection on being part of a team, you probably identified good communication as the reason your team worked well. You probably received clear instructions and everyone understood what they had to do. Or poor communication may have meant that people didn't really know what was expected of them, or they had misinterpreted instructions that were unclear. You might have considered whether you led the activity or were happy to play a supporting role. You might not have thought your part was important, but looking back on the activity you might now see that everyone has a part to play in a team.



## 3 Are you listening or waiting to speak?

Listening is a key part of the communication process and to do it well you need to use your sense of sight as well as hearing. Remember we talked about visual communication in the first section?

We can generally process information quicker than we can convert it into a spoken response, so there is a risk that our mind tends to wander. Active listening is about consciously focusing for a specific purpose and is an essential part of activities like counselling or attending meetings and reviews about the people you are supporting. To be an active listener you need to clarify and confirm the other person's spoken thoughts, as well as taking in their non-verbal messages.

- How long do you actually listen to another person before interrupting?
- How quickly do your own thoughts take over and you start thinking about what question to ask or how to reply even before the other person has finished speaking?
- Do you find yourself interrupting the person to give your own opinion or to finish their sentences before they are finished?

### 3.1 Listening is not the same as hearing

Hearing refers to the sounds that you hear, but listening needs you to focus. Listening means paying attention not only to the words but to how they are said.

- What kind of language is being used?
- What is the tone of voice telling you?
- What does the person's body language tell you?

You need to be aware of both verbal and non-verbal messages, and your ability to be a good listener depends on how well you see and understand these messages.

#### Activity 8

Allow about 15 minutes

Watch this TED talk about the art of active listening.

Video content is not available in this format.

[Active listening](#)



Katie Owens tells us to remember three key words if we are going to be active listeners. They are:

- Be
- Here
- Now.

What do you think she means by this? Write your answer below.

*Provide your answer...*

### Discussion

Katie Owens says that we should be present for the person we are listening to. We need to be in the moment with them, not doing anything else or distracted by anything else, such as mobile phones or having one eye on the television. It is also helpful to sum up what someone has told you, to give them the chance to check whether you have listened correctly and have understood what they have told you.

## 3.2 Do we always need to be active listeners?

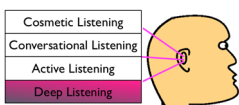


Figure 3 Four levels of listening

The next activity is about the way we listen in different situations, and you can see how the different 'levels' of listening work for us each time.

## Activity 9

Allow about 15 minutes

Read the article from [BeWellTeachWell](#) (Teacher Support Network and Robert Latham, 2016) about the different levels of listening, and think about the situations when you might use each level.

### Discussion

There is room for all types of listening in our lives.

We use *cosmetic listening* when we are 'passing the time of day', chatting at the bus stop or waiting in a queue. It is for times when what the other person is saying doesn't really matter and you don't need to act on what they are telling you.

*Conversational listening* is when you know you have to respond to the other person and think a bit about what they are saying. You might be chatting to a colleague at work or to friends and family about what you will watch on TV or where you are going at the weekend.

You may have used *active listening* in discussions about the care of the people you support. The listener uses gestures or facial expressions, sometimes asking questions or repeating back what the speaker has said for clarification. Often the listener is thinking about what response is required.

*Deep listening* is for conversations that need recording or are really important; for example, if a person is talking about an abusive situation in their life. At times like this you are paying such close attention that you don't really think about anything other than what the person is saying to you.

## 4 Ways to communicate better

You may find it easy to understand some of the people you care for but you struggle to understand others. This can be very frustrating and lead to behaviour that you find difficult to deal with. Imagine how it must feel to be trying to tell people what you want or how you feel, and everyone seems to be getting it wrong. It can also prove stressful for carers when they have to pass on sensitive or upsetting information and the person they are caring for doesn't understand them.

Look at this video on [non-verbal communication \[Transcript\]](#). Communication is vital to our well-being and quality of life. As noted by East Sussex Total Communication (2009), 'it impacts on our relationships, choice, control, emotions, self-esteem and self-expression'.

Imagine that you have a very limited understanding of speech and you are unable to express your feelings. The people around you don't understand you. Imagine that you keep trying to communicate in your own way but they just keep on speaking to you.

You don't make a fuss so they sit you in a chair in the lounge all day, every day and they think you are happy to sit there because you don't make a fuss.

Imagine that you try a different way of communicating and then they say you are too challenging to take out. So now you sit in your chair in the lounge all day, every day.

(Source: Total Communication Film (2009), presented in Total Communication Resource Pack)

It is essential that we have a method of communication; an opportunity to communicate and a subject to communicate about.

In order to make communication accessible to everyone, you need to use all the methods available to you to give and receive information.

Aids to communication include gestures, body language, signs, symbols, photographs, objects of reference and electronic aids. All these can be used to support speech or as an alternative to speech.

One really important point that we can all put into practice is to give people time to process information. Whether it's Alzheimer's, learning disabilities or just a difficult environment, if you are looking for a response try to count for 20–30 seconds in your head before speaking again or repeating the question. Every time you speak the person has to start the process of formulating an answer again (and again, and again!), which can be frustrating for both parties.

### 4.1 Dementia

You may be caring for a person or people with any of the various forms of dementia, and the [Alzheimer's Society](#) website is very helpful with advice and support, but below is an article from the Alzheimer's Association of America that has some very clear information about communicating with people with dementia. You will learn more about cognitive disorders such as dementia in Section 2, [Mental health awareness](#).

## Activity 10

Allow about 20 minutes

Read [Communication and Alzheimer's](#), an article from the Alzheimer's Association. Then answer the questions below.

- What response is suggested if the person you are supporting cannot find a word?
- Why should you keep trying to communicate, even when the person doesn't respond?
- How can improving your listening skills help you to communicate with someone with dementia?

*Provide your answer...*

## Discussion

If the person uses the wrong word or cannot find a word, encourage them to 'have a go' but be careful not to cause unnecessary frustration. While a person with dementia may not always respond to your efforts to communicate, he or she still needs the stimulus of continued communication. There will be times when they will respond so it's important to keep trying, although you should choose your words carefully.

By improving your listening skills you will be more likely to spot changes in a person's ability to communicate. In the early stages of dementia, the person's communication may not seem very different but as the condition progresses, you may recognise other changes such as using familiar words repeatedly or inventing new ones for familiar objects. The more closely you listen, the more likely you are to spot these signs and be able to help them to continue communicating as long as possible.

## 4.2 People with learning disabilities

[Mencap](#) gives this advice for communicating with people with learning disabilities:

'As long as they have the right support to learn, people with a learning disability can achieve anything. As long as you communicate that support to somebody in an understanding way.'

It is important to always use accessible language, and to avoid jargon or long words that might be hard to understand. You should also take into account any physical disabilities the person may have that could make communication difficult for them.

- **In person:** many people with a learning disability have told Mencap that the best way to communicate with them is face-to-face and one-to-one.
- **In writing:** in writing, it is a good idea to use bigger text and bullet points, and to keep writing at a minimum of 16 point. It is also important to remember that too much colour can make reading harder for some people.
- **On the phone:** the best way to talk to someone with a learning disability on the phone is slowly and clearly, using easily understandable words.

[An insightful comment from someone with a learning disability.]

‘When I had to go to the hospital the doctors would usually speak to my mum rather than speak to me. So I didn’t bring her to the hospital anymore. Finally they started to recognise I’m the one, I need to understand, not my mum.’

(Source: Mencap, 2016)

Some people have communication difficulties that are a result of a brain injury, such as a stroke, and have to learn to communicate in a different way as part of their recovery. Some ways of supporting this are as follows:

- Give the person your full attention and try to avoid any background distractions. Try to speak clearly at a normal volume.
- Listen and watch for the person’s reactions; remember – not all communication is verbal.
- Don’t try to speak for the person, or finish their sentences.
- Don’t pretend you’ve understood the person if you haven’t, or try to speak for them.

### Carer’s tip from Scope

Often, we do so much for people they don’t have the need or opportunity to communicate. This is where ‘sabotage’ can come in. Put important objects in a place where the person needs to ask for them; give a meal with no cutlery (again, so they have to ask). Find ways to manipulate situations to necessitate communication.

(Source: NHS, 2016)

## 5 Recording and reporting

Whether your role is to support a family member in their home, or in yours, as an unpaid carer or whether you work in a paid social care role, you are likely to have to maintain some kind of record or communicate with others in writing. These may be official or unofficial documents, but they need to be accurate, factual, clearly written and kept confidential if they contain personal information.

If you work in a paid role, the organisation you work for will have policies in place regarding record-keeping and reporting of incidents and you should be aware of these and follow procedures.

If you are an unpaid carer, any records you keep will be helpful in informing social care and medical services about changes of condition or changing care needs for the person you are supporting, and also changes in your own needs. You should always remember that your needs as a carer are also important, and well-documented records can lead the way to increased support for you in your role as well as for the person you care for.

A diary or communication book will help keep everyone informed about what is going on in the life of the person you are supporting, such as social events and medical appointments, as well as reminders for anyone else who may be supporting the person; for example, ordering medication or collecting prescriptions. Bear in mind that this is a public record, and that you shouldn't record anything in there that is private or confidential.

Communication books are not an appropriate place to write personal comments or criticisms of other staff members. You shouldn't use them to have ongoing 'conversations' with other members of staff.

### 5.1 Appropriate communication in the appropriate place

When thinking about record-keeping and reporting, one of the important things to remember is that there is a right way to record and there is also a right place to record.

#### Activity 11

Allow about 5 minutes

Read these two different messages left for the next shift in a supported living unit.

1. A message in the communication book: 'John I cleaned the kitchen for you AGAIN'.
2. A note written on a scrap of paper and left on the table: 'Brenda needs to be taken to the doctor as soon as possible'.

Was there anything inappropriate about these messages? If so, what would you do instead?

*Provide your answer...*



### Discussion

The message about cleaning the kitchen does not belong in a communication book. It is a conversation about roles and responsibilities that should take place between the people involved or with a line manager if appropriate.

The message about the doctor is very important and should be in a communication book or on a message board. It should also be communicated verbally to the next person on shift. Notes written on bits of paper can easily be lost, especially if left in a place that is constantly in use.

If you work as a paid carer all records you keep are legal documents and may be used as evidence in court. This means that anything you write should be dated and signed by you, leaving no space for additional information to be inserted.

It is important that all records are factual. You should report only what you actually know or have seen, not your opinion of why it happened or how the person was feeling, unless they are actually able to tell you this information.

For example, you should not record a statement like 'Dad had a good night' unless he tells you himself that he had a good night. Instead, you could write something like 'Dad appeared to be asleep every time I checked'.

### Activity 12

Allow about 10 minutes

Look at these statements and rewrite them in a way that is factual and accurate, not using any language that can be interpreted differently by different readers.

1. I was tidying Mr Brown's bedroom when he suddenly kicked off and pushed me out the door.
2. Joan really enjoyed her lunch and loved her trip to the garden centre.
3. Eddie got out of bed on the wrong side today. He's been in a really bad mood since breakfast.
4. I think Mum is feeling depressed. She seems in a really low mood.

*Provide your answer...*

### Discussion

1. Did Mr Brown want you in his bedroom? Perhaps you should have asked his permission first. How would you record that? This statement says more about the way the carer has behaved, which is not respectful of Mr Brown's privacy. Perhaps you could say 'I knocked on Mr Brown's door and he didn't answer, so I went in to see if he was all right. He didn't speak to me so I started to put some of his clothes away. He said in a loud voice "Get out and leave me alone". Then he took hold of my arm and pushed me towards the door'.
2. Did Joan tell you she enjoyed her lunch? Can you honestly say that you know that? Perhaps it would be more accurate to write: 'Joan finished her lunch and didn't refuse any of it. In the afternoon we all visited the local garden centre'.
3. Why has Eddie been 'in a bad mood' since breakfast? Has he told anyone? Maybe he is in pain? Maybe he wanted something different for breakfast and

nobody asked him? You could write 'Eddie appears to be agitated this morning. He refused his breakfast and was pacing up and down the kitchen for 20 minutes and wringing his hands' and then try to find out what the problem is.

4. What has Mum said to make you think she is depressed? What exactly is a 'low mood'? Would anyone who read it know what it meant? You could say something like 'Mum has been much less talkative than usual and has not wanted to go out when I have suggested outings recently. Her appetite seems to have reduced as she is only picking at her food. She spends a lot of time just sitting in her chair. I asked if anything was wrong, and she said she "just can't be bothered with anything"'.

You are probably thinking now that it all seems very complicated, but it gets easier. When you record information about the people you support, try to get in the habit of reading it back and asking yourself 'Is it fact or opinion?' and 'Does it paint a clear and factual picture of events?'.

It all comes with practice, and if you can share the task with another person you will be able to work together on improving your record-keeping and reporting skills.

## 5.2 Language and perception

It is important that you consider the way the language you use will be received by others. It is absolutely not all right to swear at or about the people you are supporting, or your colleagues. What some people call 'banter' may be seen as offensive or prejudiced behaviour by others, and you always need to be aware of how others may perceive what you say.

However, we have already discussed the fact that some of the people you support may use words or behaviours that you find unacceptable and difficult to deal with. This may be because of your own backgrounds and beliefs or sensitivities, but you do have to find a way to deal with this without resorting to retaliation.

There will be times when you have to record incidents involving the behaviour of people you support, and if you do, it is very important to do this accurately. It's no good saying 'He swore at me' or 'He kicked off' because this is not helpful for anyone trying to assess the incident or trying to prevent it happening again.

If you need to record an incident and it involves someone swearing, it is important that you write down *exactly* what they said, even if you find it hard to do.

Also, if there is an incident that needs to be recorded you must write exactly what you saw happen, and nothing else. It is also helpful to write down what had been happening just before and the result of the incident. This again is so that anyone trying to assess the person's behaviour has a clear picture of what happened without it being clouded by other people's opinions or judgements.

## Key points from Section 1

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In this section you have learned:

- that everything you do or say is communication
- the importance of visual communication when caring for others
- what interpersonal skills are and some of the ways you can develop them
- the different stages of listening and the role that active listening plays in communication
- that there are different ways to help people to communicate
- why good record-keeping is important and what makes a good record.

Section 2 covers mental health problems. Studying this section will give you an insight into the care and treatment options for people with a mental illness. You will also learn about the role of family carers looking after a friend or a relative with mental health problems.

## Section 1 quiz

Well done; you have now reached the end of Section 1 of *Caring for adults*, and it is time to attempt the assessment questions. This is designed to be a fun activity to help consolidate your learning.

There are only five questions, and if you get at least four correct answers you will be able to pass the quiz.

- I would like to try the [Section 1 quiz](#).

If you are studying this course using one of the alternative formats, please note that you will need to go online to take this quiz.

## I've finished this section. What next?

You can now choose to move on to Section 2, Mental health awareness, or to one of the other sections.

If you feel that you've now got what you need from the course and don't wish to attempt the quiz, please visit the [Taking my learning further](#) section. There you can reflect on what you have learned and find suggestions of further learning opportunities.

We would love to know what you thought of the course and how you plan to use what you have learned. Your feedback is anonymous and will help us to improve the courses that we offer.

- Take our [Open University end-of-course survey](#).

We're really interested in hearing from you about how you found the course, whether it has been helpful to you and what we could improve. Your feedback is anonymous but will have massive value to us in improving what we deliver.



# Mental health awareness

## 1 Terminology and mental health

In the introduction to this section of the course you will have noticed that a number of different terms are used to describe the experience of people who for one reason or another have been associated with mental health issues. These issues are described as mental health problems, mental ill-health and mental illness. Other ways to describe mental health problems include mental disorder, mental disability, mental distress and mental incapacity. Many people understand mental health problems because of specific conditions. Later in this section you will learn about some of the types of mental health problems, including:

- depression
- schizophrenia
- bipolar disorder
- dementia.

In this course we are using the term 'mental health problems' because it suggests that the condition brings with it wider issues than an individual's mental health status implies. Note the term 'mental health problems' is used in the plural. The person can often have more than one problem associated with their condition.

### Activity 1

Allow about 10 minutes

Consider what you think is meant by good mental health and how it might differ to having mental health problems. Jot down your thoughts in the box below.

*Provide your answer...*

### Discussion

The difference between having good mental health and experiencing mental health problems is a contested area. Good mental health is not just the absence of mental health problems. It is, instead, a positive state of well-being in which the individual:

- is able to make the most of their potential
- copes with the everyday things that happen in life
- can play a full part in the lives of others.

However, many people with mental health problems argue that they can attain their potential, cope with life and enjoy fulfilling relationships as long as their particular

needs are met. Others, of course, do not enjoy this positive state of mental health and require ongoing care and treatment.

## 1.1 The biomedical model

The most common way to understand mental health problems is by seeing them as an illness in the same way as other health problems, such as cardiovascular disease or diabetes, are seen as illnesses. Policymakers encourage us to do this. Underlying the biomedical model is the belief that mental illness has a cause that can be treated and, in many cases, cured.

The biomedical model has its advantages:

- It offers explanations of mental ill-health that many people who experience mental health problems find reassuring as it can be the first stage towards recovery.
- Diagnosing and naming conditions can help to reassure people that what they experience is 'real' and shared by others.
- Relieves symptoms such as hallucinations, a rapid heartbeat or constant worrying so that the individual starts to feel better.
- Provides access to help and support that can help to alleviate some of the things that trouble the individual, such as not being able to go shopping.

However, the biomedical model is founded on the assumption that:

- the cause of the mental illness lies within the individual so the focus of treatment is on bodily symptoms
- there is a focus on what is normal so that medical judgements determine what is not normal.

The biomedical model has shortcomings that a more holistic model might explain.

A holistic model of mental health takes into account the physical, spiritual, psychological, emotional, social and environmental components of our lives. In other words, it takes into account our person and everything about our life as a whole.

## 1.2 Stigma and discrimination

People who suffer from mental health problems often find that the causes of their distress do not lie within them but can be found in the situations in which they find themselves. For example, poor housing on noisy estates where the person feels isolated is more likely to lead to mental health problems than a well-supported home in a quiet and friendly environment. Today, being subjected to prolonged stress from work and the other demands made on people is a major cause of mental health problems.

Traditionally, people have tended to see others with mental health problems as being different. The result is that those with mental health problems have become cut off from the 'normal' social life that most people take for granted, such as good employment opportunities and wide social networks. This can also lead to two particularly damaging consequences: people with mental health problems can experience stigma and discrimination.



## Stigma

Due to stigma, people with mental health problems are disapproved of. They are not seen as a person in their own right, but only as having a mental illness. Stigma can make their mental health problems worse because it isolates them, and consequently the mental health problems are harder to recover from. It is the mental illness that other people see and not the person. In this way people with mental health problems are also discriminated against.

## Discrimination

Discrimination is the harmful treatment of an individual or group of individuals because of a particular trait or characteristic. Although the Disability and Equality Act 2010, which applies across Great Britain, explicitly forbids any form of discrimination, people with mental health problems might still experience indirect discrimination. For example, they might be excluded from sports clubs on the grounds that they do not fit in or excluded from up-market shopping centres where their presence or appearance offends consumers. They might also not have their mental health considered when they are at work; for instance, being exposed to stressful situations or meeting unrealistic targets.

### 1.3 The legal framework

In England and Wales mental health practice is governed by two main pieces of legislation. The Mental Health Act 1983/2007 provides the overarching law on how care and treatment is offered, with provision for individuals to be sectioned if necessary. This means they can be made to accept treatment against their will in some carefully regulated circumstances.

The Mental Capacity Act 2005 is used to ensure that vulnerable people, particularly older people who are unable to govern their own affairs, are not exploited or harmed. If this is the case, Power of Attorney can be made so that another person takes on the legal authority to act on behalf of that individual. This often happens when an older person develops dementia and can no longer make decisions; for example, to manage their finances or other everyday tasks. If you want to read more about the Mental Capacity Act, see Section 4 of this course, [Positive risk-taking](#).

Scotland has its own mental health legislation: the Mental Health (Scotland) Act 2015. The Mental Health (Northern Ireland) Order 1986 governs care and treatment in Northern Ireland.

It is worth noting that most people who use mental health services do so on an informal or voluntary basis, and are not obliged to accept treatment if they do not wish to do so.

## 2 Types of mental health problems

Some mental health problems are common and many people with good mental health know what the problems feel like. It is estimated that one in four people will experience mental health problems at some point in their life, while at any one time one in six people will experience mental health problems. The majority of these people have depression or anxiety. Mental health problems are difficult to see; consequently they are not accepted as an illness in the same way as physical illness or disability.

In this section we focus on mental health problems that have an effect on people's lives in one way or another. You will probably have heard of many of them.

### Diagnoses

Before you study types of mental health problems, we'd like you to reflect on any diagnoses that you have heard of or had experience of.

#### Activity 2

Allow about 10 minutes

Make a note of any mental health problems that you are aware of.

- What is its/their name(s)?
- What signs and symptoms might the mental health problem lead to?

*Provide your answer...*

#### Discussion

Some mental health problems are common and many of the signs and symptoms are a familiar experience to most people. Some of the symptoms, for example, are part of the 'normal' way that people react to changes in their circumstances; strong feelings of sadness and guilt during a bereavement is normal, but it is not so normal in the absence of a bereavement. Some mental health problems feature symptoms that are not part of the normal experience for most people; hearing voices and holding odd beliefs about other people are two examples.

You will now consider types of mental health problems as they are classified in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD). It is worth remembering that these are based on medical diagnoses and so are largely based on a biomedical model. When making a diagnosis professionals rely on a combination of signs and symptoms, as well as other information such as that gained from blood tests.

Signs are what another person can observe, whereas symptoms are what the individual experiences or feels. A mental health professional will try to observe for signs or ask another person known to the individual to talk about any signs they have observed, and

seek information from the individual about their experience by questioning them during the mental health assessment.

Classifications of mental health problems and their common signs and symptoms are described next.

## 2.1 Mood disorders



Figure 1 There are many different types of mood disorder

Mood disorder does not just refer to whether you are angry (in a bad mood) or understandably happy at hearing good news (in a good mood). Rather, mood refers to the individual being in despair and very sad (low in mood) or ecstatically happy and elated (high in mood).

Being in a good mood or being in a bad mood are common human emotions and we all have experienced them at one time or another. However, when there is an extreme tendency where a person's mood is very low or very high for a prolonged time, then it might be due to diagnosable mental health problems. Mood disorders include depression, mania and bipolar disorder.

### Depression

When an individual is in a very low mood they are termed as depressed. Signs and symptoms of depression include:

- Changes in appetite: the individual might eat more than usual or lose their appetite completely. This can result in weight gain or weight loss.
- Sleep changes: the individual is likely to have trouble getting off to sleep or is waking in the early hours. In the morning they will not feel refreshed and will feel tired most of the day.
- Feeling sad (crying a lot), without hope, and feeling guilty much of the time. Signs to other people include the individual seeming very negative in outlook and lacking motivation.
- Feeling tired, overwhelmed and pressured, lying in bed and isolating oneself.

### Mania

Mania is rare but does occur at times. Typically, a person who is in a manic state might display the opposite signs and symptoms to a depressed person.

- The individual might be very active, or even overactive, so that they lose weight through missing meals or exercising excessively.

- The individual might be seen by others as overenthusiastic, over joyful and ecstatic even if there is no obvious reason for such high emotions. At times it can result in recklessness and not considering the consequences of their actions properly.
- The individual might complain that their thoughts are rushing so that they cannot concentrate on a task for very long and are easily distracted.

## Bipolar disorder

Bipolar disorder used to be known as manic depression. Individuals who have bipolar disorder experience the highs of mania alternating with the lows of depression.

## 2.2 Anxiety disorders



Figure 2 Panic attacks can be a feature of panic disorder

When a person has a panic attack they breathe fast and deep, exhaling a lot of carbon dioxide ( $\text{CO}_2$ ) so they will feel faint. If they blow into a paper bag and then re-breathe from the paper bag they take in some of the  $\text{CO}_2$ . It helps to slow down the breathing so that the person feels better.

As the name suggests, anxiety disorders occur where the person feels unusually anxious, either in the short term or for a prolonged period. There are several types of anxiety disorder:

- General anxiety disorder in which the person feels fearful or anxious for a long time but without any obvious cause.
- Panic disorder in which the person has panic attacks that can be unpredictable.
- Phobias, which are an intense fear of something that triggers anxiety.
- Obsessive compulsive disorder (OCD), which causes the person to have intrusive thoughts or urges to do something, such as cleaning excessively, and an overwhelming desire or compulsion to repeat tasks such as checking locks or flushing the toilet.
- Post-traumatic stress disorder (PTSD) is an anxiety associated with a bad experience in which the person relives the fear and anxiety that they felt during that bad experience.

## 2.3 Psychosis

Psychoses are a group of serious mental health problems where the individual loses touch with reality. This experience is not something that most people can identify with and so the behaviour of an individual who is psychotic can seem very odd. The best-known

type of psychosis is schizophrenia. A diagnosis of schizophrenia in most cases means that the individual is referred to specialist mental health services.

## Schizophrenia

Many people think of people with schizophrenia as having a split mind. This is not the case. It does mean, though, that many people who have schizophrenia lose some of their personality – it is described as ‘fragmented’. This is largely due to the way schizophrenia affects people. The effects of schizophrenia are broadly divided into so-called positive symptoms and negative symptoms.

Positive symptoms are named positive, not because they are necessarily a good thing but because they add something to the person. For example, a diagnosis of schizophrenia is usually made when certain symptoms are present – that is, the symptoms are added to the person.

There are typical examples of positive symptoms that are indications of psychosis and schizophrenia. The individual might display odd behaviour as a response to symptoms including hallucinations, delusions or other disordered thought processes.

- Hallucinations are sensory perceptions where there is no external stimulus. For example, an auditory hallucination such as hearing voices occurs when there is nobody speaking.
- Delusions are strongly held beliefs that other people don't share. For example, the individual might believe that their neighbour can read their thoughts.
- Thought disorders include thinking that the television news is referring to that individual specifically or that the individual thinks that other people can control them through special cognitive powers.

In schizophrenia the individual might also feel very lethargic, unmotivated and seem to others disinterested in what is happening around them. They might be unable to look after their immediate environment without prompting. These are examples of the negative effects of schizophrenia – they take away from the individual.

## 2.4 Dementia

Dementia is an umbrella term used to describe a wide range of cognitive disorders. In cognitive disorders the individual loses their ability to think and might even lose their memory completely. Complete amnesia is very rare but the most common and prevalent type of cognitive disorder is dementia. The best-known type of dementia is Alzheimer's disease. It is found mainly in older people but it can occur much earlier as a pre-senile dementia. Other well-known types of dementia are vascular dementia, frontotemporal dementia and dementia with Lewy Bodies.

Features of dementia include:

- gradual memory loss
- inability to think through problems in everyday life
- inertia (inactivity)
- losing the ability to communicate and interact appropriately.

The [Alzheimer's Society](#) has useful information about dementia, such as diagnosis and caring for a person with dementia.

## 2.5 Other disorders

### Eating disorders

Anorexia nervosa and bulimia are the best-known eating disorders. While they are often associated with young women and adolescent girls, each can occur in both genders and throughout the age range.



Figure 3 Anti-anorexia campaign

In anorexia the individual aims to lose weight. They will eat very little and purge their body (through vomiting or taking laxatives) to do so. It is thought that disordered body image and views about food and appearance cause severe weight loss. In contrast, individuals with bulimia are likely to binge eat before purging the body; for example, by making themselves vomit.

### Personality disorders

This is often referred to as BPD – Borderline Personality Disorder. It describes individuals who demonstrate challenging or anti-social behaviour caused by their disordered thoughts. Individuals might have poor coping skills, so that they get easily frustrated with life challenges, which in turn can lead them into prolonged conflict with family and friends. Due to the difficulty in forming proper relationships, many might self-harm repeatedly and are often described as attention seeking.

### Substance-related disorders

Individuals who might be classified as having a substance-related disorder are dependent on drugs, alcohol or other addictive substances. Sometimes freely available drugs, including so-called legal highs, can contribute to mental health problems. Substance misuse can cause both physical and mental health-related problems. If there is substance use or alcohol abuse in conjunction with other mental health problems such as schizophrenia, it can increase the severity of the symptoms. This is usually referred to as dual diagnosis, where specialist services for substance misuse and mental health problems are both involved in the care and treatment of the person.

The types of mental health problems we have described suggest that classifications are clear-cut but this is not always the case. Sometimes the differences between them are blurred. To better understand how mental health problems affect individuals we would like you to now turn to the personal experience of two people who have lived with mental health problems.

## 3 Experiencing mental health problems

An understanding of the effects that different types of mental health problems might have on the individual is best gained by hearing what people who live with mental health problems say about their experiences.

You will now watch a short video by the actor and TV presenter Stephen Fry who articulates the numbing effect his bipolar disorder can have. Note that the video is titled manic depression and not bipolar disorder, reinforcing that terms change as our understanding and ideas about mental health problems evolve.

### Activity 3

Allow about 25 minutes

View the video *The Secret Life of the Manic Depressive Part 1*.

View at: [youtube:TcPRF9slENI](https://www.youtube.com/watch?v=TcPRF9slENI)

Stephen Fry talks about his depression

As you watch the video make brief notes on any signs and symptoms that Stephen Fry describes.

Provide your answer...

### Discussion

Fry talks about his frustration and misery as he describes the effect that his bipolar disorder has on his life. In the video he focuses on the depressive features of his mental health problems. You will have seen how he suffered; he wanted to be alone, he felt guilty that he had let other people down, and felt a tremendous sense of misery and failure. He doesn't discuss the reckless and impulsive behaviour during the manic phases he has also experienced. If he had, he might have told of his shoplifting sprees and of how he was on the run from the police. It was when he was a young offender in prison that he was first diagnosed as having mental health problems.

You will continue to gain the perspective of people who have experienced mental health problems by reading two transcripts of a case study that give two views of how depression affected Kate.

### Activity 4

Allow about 20 minutes

In this excerpt taken from *Lorraine and Kate: Depression* (OpenLearn, 2016), you will read how Lorraine noticed how work was taking its toll on her friend Kate. You will then have the opportunity to read about Kate's own perspective.

Note in the response box below any life stresses that had a harmful effect on Kate's mental health.

### Part 1: Lorraine's story

I've been friends with Kate since we were at primary school. After school I went to work for an estate agent, got married and now have a toddler and am expecting again. I still work at the estate agent, part-time. Kate got a job working for someone in a big firm in Leeds.

She lived with her mum and dad and travelled daily at first. We saw each other most weeks, went for a drink at our local, to the cinema, that sort of thing. Then Kate moved into a small bedsit in Leeds but she mostly came home at weekends and we kept in touch.

When Hayley was born she thought she was cute and would drop in to see us. We got a routine of us going out for the evening every other week. Kate's job seemed very pressured. She had to have her work mobile on all the time because the people she worked for were overseas a lot and they could ring her any time.

So she didn't want to go to the cinema or to the leisure centre in case she missed a call. Our nights out became less regular and when we did go out they were less fun, she seemed to be edgy.

We went away for two weeks' holiday and we hadn't arranged another meeting. Kate said she would ring when she was free. Weeks went by and it was a relief when she did ring. She said she didn't want to meet because she wasn't well. She was 'signed off'. When she told me it was depression I told her how glad I was it wasn't something serious.

That was over a year ago. I know now that depression is serious and that I said the worst thing possible. But I didn't know and I hope I've been a good friend all the same. Kate hasn't gone back to the job in Leeds but she's much better although her medicine is still not quite right for her.

(Source: OpenLearn, 2016)

Sometimes when they try a change of pills she gets side-effects and feels awful but she's the old Kate again.

Now read what Kate said about the stress she was under.

### Part 2: Kate's story

Looking back I don't really know how this happened to me. I suppose I did work too hard and I hadn't had a proper holiday. How could I afford one, the money I'm chucking at my landlord? The best I could do was to go back to Mam's.

I just reached a point where work overwhelmed me. The inbox seemed to just fill, and I'd work harder and harder, but more and more things to do would appear. I felt stressed and anxious the whole time.

There were just some days I could hardly get out of bed because I knew what was waiting for me when I got to the office. And I was so tired as well, constantly tired. I had been keen on running, but that went out the window – even if I'd had the time, I could barely lace my shoes never mind get round the park.



I was lucky; I was at home when I 'broke down'. It was a Monday morning and I just couldn't get out of bed. Mum came in to see what had happened and I just started to cry and cry and couldn't stop.

I couldn't even talk to her, I just cried. She was worried, so she got me straight down to the surgery and our GP was great. He took it seriously – which surprised me, to be honest. Thank God for that.

It's a year later, I still have regular check-ups because I'm not back to normal and the medication still isn't right. There are days when I don't want to see anyone and I find crowds dreadful.

When I meet people I have to work hard at concentrating on what they are saying. Friends think I'm OK but I'm abnormally tired after being with them. Apart from thinking depression wasn't serious Lorraine has been great and I just love seeing her and Hayley.

Watching Hayley crawl around takes me out of myself. I can see that I still worry too much. I realise it is me; I wasn't over-worked – I'd got things out of proportion. Yes, I can see what went wrong but I still don't know why.

(Source: OpenLearn, 2016)

*Provide your answer...*

### Discussion

You have read about the same situation from two perspectives. First Lorraine tells us how she observed Kate change from the good friend she used to know to the more distant and 'edgy' Kate. Kate's symptoms match many you have read about earlier: feeling overwhelmed, being stressed and anxious, constantly tired, staying in bed, crying a lot and isolating herself. These are all typical signs and symptoms of depression.

What life stresses did you note that affected Kate? She was, perhaps, overworked without adequate time to relax between work days, being pressured to perform for her employer, and she had money worries (the rental on her flat). It was all at a time when she moved away from her support network – Lorraine and her mum.

In the next topic you will learn more about some of the interventions commonly used to alleviate mental health problems.

## 4 Mental health care and treatment

During the twentieth century, care and treatment of the mentally ill developed from an institutional system based in large mental hospitals to a largely community-based care system. The old mental hospitals provided custodial care, which required patients/inmates to live in a self-contained hospital community, supervised by a separate community of doctors, nurses and other service workers, such as an upholsterer, head gardener and cobbler. Today's community care has most service users living independently, in small groups or with their own families, in the same community where the rest of us live.

Care and treatment has also evolved. The introduction of effective medication in the 1950s led to the gradual closure of the old hospitals and less need for constant supervision of individuals with serious mental health problems. Concurrently, new talking therapies were introduced that helped individuals to cope with life's stresses. Today there is a range of effective medication that is used to treat mental health problems from schizophrenia to depression. Whereas at one time the goal was the containment and alleviation of symptoms, today the goal of treatment is recovery.

### 4.1 Recovery



Figure 4 The road to recovery

The concept of recovery acknowledges that the individual with mental health problems wants to have a meaningful and satisfying life, and it is the individual who defines for themselves what is meaningful and satisfying. With support from professionals, carers and fellow service users, the individual moves forward to attain their goals.

In their factsheet on recovery, [Rethink](#), a major mental health charity and campaigning organisation, describes recovery as having the following components:

- working towards your goals
- having hope for the future
- something you achieve for yourself
- being an ongoing process
- taking responsibility for one's life.

(Source: adapted from Rethink, 2014)

This, of course, depends on what is realistic for each individual.

## 4.2 Therapies

Today there is a wide range of medicines used specifically to treat mental illness, e.g. antipsychotics to treat schizophrenia and psychotic disorders, antidepressants for depression and anxiolytics to alleviate the symptoms of anxiety.

Talking therapies such as cognitive behavioural therapy (CBT) are now commonly prescribed, either as an alternative to medication or in conjunction with tablets. These recognise that the individual should be involved in their own recovery. They take the form of a programme guided by a therapist and which the person follows, doing 'homework' to practise what they learn. Examples are psychological help to overcome fears or other constraints to leading a full and active life.

Talking therapies are often used to treat irrational worries such as a fear of open spaces or heights. The therapist might think the appropriate treatment is a course to desensitise the person to being outside their house. In this psychological therapy the person would be exposed gradually to the situation that the phobia is about while carrying out a relaxation activity.

### Activity 5

Allow about 15 minutes

You will now match a treatment with specific mental health problems. Read the four scenarios below. When you have finished, select what you think is an appropriate treatment from the list.

#### Scenario 1

Ray has money worries. He overspent at Christmas and now finds it hard to pay back loans he took out. Understandably, he is unhappy and now feels guilty that he cannot afford to take his family on a holiday as he promised. He has been to his GP who diagnosed depression.

What would you say would help him most?

- ☐ Antipsychotic medication
- ☐ CBT with antidepressant medication
- ☐ Counselling for PTSD
- ☐ Admission to a mental health unit

#### Discussion

As Ray has depression, the use of antidepressants at the same time as talking about his problems is probably the approach that would help him the most.

#### Scenario 2

Betty last went out of her house two weeks ago. She was accompanied by her daughter to the shops. Betty had to return home early because she felt frightened.

- ☐ Sectioning under the Mental Health Act
- ☐ Desensitisation for a phobia of open spaces (agoraphobia)
- ☐ Antidepressant medication
- ☐ A leaflet on self-help

### Discussion

It is most likely that Betty has a phobia, for which the appropriate treatment is desensitisation.

### Scenario 3

Carl heard voices, which he thought came from inside his head. He believed that they had been put there by work colleagues he didn't get on with. He decides to stop going to work.

What would you say would help Carl most?

- ☐ CBT with antidepressant medication
- ☐ Sectioning under the Mental Health Act
- ☐ Antipsychotic medication
- ☐ A paper bag

### Discussion

It sounds like Carl has psychosis, which might develop into schizophrenia. Antipsychotic medication would help him at this stage of his mental health problems.

### Scenario 4

Maya was in a car accident a year ago. When she gets in her boyfriend's car she feels anxious and keeps thinking about the car crash. She can almost hear the noise.

What would you say would help Maya most?

- ☐ Counselling for PTSD
- ☐ Sectioning under Mental Health Act
- ☐ Antipsychotic medication
- ☐ Desensitisation to car crashes

### Discussion

As Maya has PTSD the best approach is to offer her counselling, a type of talking therapy.

## 5 Carer experience



Figure 5 Supporting each other

Mental health problems can have a huge impact on relatives and friends who support the cared-for person. They can be emotionally draining and upsetting, and many carers are not prepared for their new role. However, many carers also find a sense of achievement in their caring role and the relationship with the cared-for person becomes deeper and more meaningful.

Within this topic you will look at how caring for a family member impacts on family carers. You will examine family carers' rights, and their relationship and engagement with mental health services. You will also consider how a more carer-centred approach might help to develop a relationship between family carers and mental health services.

### 5.1 Relationships and engagement



Figure 6 A mother and daughter talking with a care professional

Caring for a relative with severe mental health problems is a distinct and unique experience and a steep learning curve for which few people are prepared. The relationship and engagement between families and professionals is therefore of great importance.

#### Activity 6

Allow about 10 minutes

Reflect on how you think family carers should be helped by mental health professionals. Jot down your thoughts in the box below.

*Provide your answer...*

#### Discussion

You might have considered that family caring in mental health is distinct from other kinds of caring and also very personal to the relationship the family has with the cared-for person. Because of this, you might think that mental health professionals should recognise that the needs of the family are not necessarily the same as the needs of the person being cared for. You might have thought that it is better if the family is involved

and included in decisions made about the cared-for person and is acknowledged as a source of expert knowledge.

It is possible that you jotted down some barriers to effective caring: carers being taken for granted and isolated. Your own experience might have led you to conclude that family carers have been trapped in the confines of their caring role and just expected to cope.

On a more positive note, you perhaps know that there are ways to overcome these barriers; for example, by taking into account family carers' rights and responsibilities. This means listening to and taking seriously what they have to say. Providing timely support and assistance demonstrates to families that their responsibilities are recognised, and that they have a valued part to play in decision making and treatment approaches. It would also be to the family's advantage to learn more about mental health and highlight any cultural diversity elements to professionals.

## Key points from Section 2

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In this section you have learned about:

- the terminology used to explain mental health problems
- particular types of mental health problems
- the effect mental health problems might have on the cared-for person
- specific examples of care and treatment
- the impact mental health problems might have on family carers.

Section 3 looks at palliative and end-of-life care. Studying Section 3 will show you how to maximise the cared-for person's quality of life, as well as how to support someone to reduce trauma during the final stages of life.

## Further information (optional)

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Now you have completed this section, why not explore OpenLearn for more on mental health? The BBC, in partnership with The Open University, broadcasts topics around mental health, such as *All in the Mind*. Why don't you find out when you can listen to one of these programmes?

A large proportion of homeless people have diagnosable mental health problems. Think about what their lives must be like, and of ways in which you or others could help.

Using the internet, explore what charitable organisations and mental health campaigning groups offer. The sites for [Rethink](#), [Mind](#), the [Alzheimer's Society](#) and [Age UK](#) offer a huge amount of information, resources and advice about mental health problems.



## Section 2 quiz

Well done; you have now reached the end of Section 2 of *Caring for adults*, and it is time to attempt the assessment questions. This is designed to be a fun activity to help consolidate your learning.

There are only five questions, and if you get at least four correct answers you will be able to pass the quiz.

- I would like to try the [Section 2 quiz](#).

If you are studying this course using one of the alternative formats, please note that you will need to go online to take this quiz.

## I've finished this section. What next?

You can now choose to move on to Section 3, Palliative and end-of-life care, or to one of the other sections.

If you feel that you've now got what you need from the course and don't wish to attempt the quiz, please visit the [Taking my learning further](#) section. There you can reflect on what you have learned and find suggestions of further learning opportunities.

We would love to know what you thought of the course and how you plan to use what you have learned. Your feedback is anonymous and will help us to improve the courses that we offer.

- Take our [Open University end-of-course survey](#).



# Palliative and end-of-life care

## Introduction

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It is important to realise that everyone will die at some time – death is unavoidable. Being unavoidable, planning for death and discussing death with loved ones is a part of having a good death. It is not something that you as a carer should deny the cared-for person if they wish to talk about their wishes and fears. It is important that the cared-for person is given the opportunity to talk about their death but they should not be made to feel that they must. As either a paid carer or an unpaid carer there is only one opportunity to get end-of-life care right. You don't get a second chance for any individual cared-for person.

While the course is of value to all carers, the course team acknowledges that palliative and end-of-life care might be informal or carried out by paid care workers. While many people prefer to die at home, where their relatives care for them in their final months, weeks and days, they are often assisted by paid care workers. Some paid care workers specialise in palliative and end-of-life care.

An important consideration that is emphasised in this course is that carers need to take care of themselves as well as the person they care for. As you read, think about what support would be available to you from family or friends, or what support you might offer to family and friends should they be providing palliative or end-of-life care. You might find Section 1, [Good communication](#) (particularly having difficult conversations), and Section 5, [Looking after yourself](#), helpful also.

In this section you will study palliative and end-of-life care. You will find out how to maximise a person's quality of life by employing the core principles that underpin good-quality end-of-life care. You look at how you can enhance the dying process to help the person have a good death.

Towards the end of the section you will reflect on a case study that brings together your learning and describes signs that someone is near to death. In the case study you follow Frank and Grace during Frank's final weeks.

At the end of the section there is a short quiz to test what you have learned about palliative and end-of-life care. On successful completion of the quiz you will earn a digital badge.

This section is divided into five topics and each of these should take you around half an hour to study and complete. The topics are as follows:

1. **Palliative care** introduces palliative care as a treatment that relieves but does not cure a disease or an illness. Neither should it bring about the death of the person or delay the death. Its focus is on the physical, psychological, social and spiritual well-being of the dying person, and those close to him or her.
2. **Maximising quality of life** discusses how quality of life for a person receiving palliative care can be enhanced and personalised to the individual, while looking at how a special focus might be necessary if a child receives palliative care.

3. **End-of-life care** is part of palliative care for people who are thought to be in the last year of life. These people can be helped to have a good death, where what is meant by a good death is dependent on what matters to the person who is dying.
4. **Common core principles** describes a framework for how practitioners are guided to provide end-of-life care, while recognising that many practitioners who provide end-of-life care are not end-of-life care specialists.
5. **Approaching death** discusses what constitutes a good death as decided by the person who is dying, and recognising signs of death.

## Learning Outcomes

By completing this section and the associated quiz, you will be able to:

- explain what palliative care and end-of-life care are
- describe how someone might have a good death and the signs of approaching death.

## 1 Palliative care

Palliative care is treatment that relieves but does not cure a disease or illness. Palliative care should not bring about the death of the person or delay the death. Its focus is on the physical, psychological, social and spiritual well-being of the dying person, and those close to him or her. It is often used to mean end-of-life care but, as you find out later, end-of-life care is a part of palliative care and so it is not the same as palliative care.

### Activity 1

Allow about 20 minutes

Spend a few minutes thinking about what you understand by the term 'palliative care'. You might find it easier to reflect back on the experience of someone you know who died recently or someone who is currently having palliative care. If you have not experienced palliative care for someone you know, think about what you understand it should be.

Divide your thoughts into four criteria:

1. Physical: how is their body affected?
2. Psychological: what are they thinking about and how does it affect their emotions?
3. Social: do they have a social life or meet friends and family?
4. Spiritual: do they want to talk about the meaning of life or any faith they might belong to?

Use the box below to record your thoughts.

*Provide your answer...*

### Discussion

You know from the first paragraph in this topic that palliative care involves the physical, psychological, social and spiritual well-being of the dying person and those close to him or her.

The physical aspects of palliative care might include any medication and pain relief the person is prescribed, and body changes due to age, illness or inactivity. The palliative care focus would be on the physical comfort of the person: being at home or in a hospital is a key consideration, while pain management and hygiene are important for the dignity of the person.

Psychological aspects encompass both cognitive (thinking) and emotional effects that are important during palliative care. The person might be afraid of the process of dying, afraid of what to expect when dead, worried about how their spouse or family will cope or they may have long-standing arguments they want to settle. Palliative care would focus on communication, especially difficult conversations (you can find out more about difficult conversations in Section 1, [Good communication](#)), being given information and listening carefully to what the person wants in respect of funeral arrangements, for example, or any bequests.

The social aspects of palliative care include finding out about people the cared-for person would like to see or if there are some things the person would like to do. A palliative care approach might ensure that individuals the cared-for person cares about are informed.

Spirituality is often hidden in our culture but it does not mean it is absent. Opportunity should be given for the cared-for person to express their spirituality, whether it is through an established religion or through a less formal, although significant, part of the cared-for person's beliefs.

It's important to remember that palliative care is not confined to people with cancer, as is often believed. It might also be an approach that is used across all ages and a range of conditions, from respiratory disease to dementia.

A key objective is to improve the quality of life of the dying person and those close to them. You will now look at how quality of life can be maximised.

## 2 Maximising quality of life

A palliative care approach is more than easing the approaching death of an individual. It aims to improve the quality of life of a cared-for person who faces life-threatening illness, as well as that of their family. It does this by providing pain and symptom relief as well as spiritual and psychosocial support, from diagnosis to the end-of-life and bereavement. But palliative care also takes into consideration the preferences of people who, for whatever reason, don't want to know more about their approaching death.

A recent report for the Marie Curie Foundation revealed that most people favour quality of life over living longer (Dixon et al., 2015). Many people don't accept they are dying, or hope for a miracle cure to be found. Approaching death affects people in different ways and it is not unusual not to want to know how much time you have left.

Key aspects of palliative care are intended to maximise the quality of life for the person and their family and carers. It does this by working with people on controlling symptoms, offering practical assistance and giving emotional support. Palliative care takes a holistic approach as demonstrated by the World Health Organization's (2015) report on cancer care. You will look at key findings from this report in the next activity.

### Activity 2

Allow about 20 minutes

Read what the World Health Organization (WHO) identifies as the key elements of palliative care.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(Source: WHO, 2015)

Think carefully about the findings above and answer the following questions:

- Is death regarded as normal?

- Is support only for the dying person?
- Is palliative care used instead of other forms of treatment?
- Does palliative care include bereavement counselling?
- Is pain relief the only aim of palliative care?

*Provide your answer...*

### Discussion

In palliative care, death is regarded as a normal part of life – after all everybody dies. Yet the support offered in a good palliative care approach supports the dying person and others who need support at this difficult time, with bereavement counselling being an example after the death of the person. It allows for different treatments to continue if they are in the best interest of the dying person, which include pain relief if necessary. If these were the answers you thought of, you are developing an understanding of palliative care.

The terms ‘palliative care’ and ‘end-of-life care’ are often used interchangeably. They do, though, have a differing focus, in which end-of-life care is part of a palliative care approach. There are, of course, many practicalities associated with end of life: making a will, dealing with immediate finances, adapting the house and arranging power of attorney are often necessary.

For family and other carers there might be additional issues, such as negotiating time off work with an employer, dealing with stress and adapting to the transition. It is also important to remember that palliative and end-of-life care is relevant across the lifespan. Older people die but so do people of all ages, including children.

## 2.1 Palliative care for children

There are particular issues if children are at the centre of a palliative care approach. The child might have a *life-limiting* condition for which there is no reasonable hope of cure and from which they will die. Alternatively, the child might have a *life-threatening* condition for which treatment in an attempt to cure may be feasible but can fail, such as when operating on a tumour.

Caring for any child with a life-limiting or life-threatening condition, and who is expected to die, will affect the whole family, from his or her parents, brothers and sisters, to the wider family members. Parents might find it hard to accept that their child is going to die and young brothers or sisters might not understand the enormity of what is happening.

In addition to the overwhelming emotional needs, many parents need help with practical support, which they might not have had time to consider. Special equipment may be needed in the house or a school located that can cope with the child’s particular needs. The emphasis should be on discovering what the child can do, and not on what he or she is unable to do.

As with adults, palliative care for a child also encompasses end-of-life care. In the next part you will study end-of-life care as a part of a palliative care approach.

## 3 End-of-life care

End-of-life care is an important *part* of palliative care for people who are nearing the end of their life. It is for people who are considered to be in the last year of life, while acknowledging that this timeframe can be difficult to predict. End-of-life care aims to:

- help people live as well as possible and to die with dignity
- offer additional support such as help with legal matters
- continue care for as long as it is needed.

(Source: adapted from Marie Curie Cancer Care, 2015)

From what you have studied so far in this section you will know that holism and person-centred end-of-life care rely on understanding the dying person and their disease or illness. This depends on a good and detailed assessment that takes into account the person's wishes. In short, it helps lead to a good death.

Having a good death involves paying close attention to what matters to the person who is dying.

In the next activity you watch a video produced by the Social Care Institute for Excellence (SCIE) in which you follow the stories of two women who are approaching the end of their lives. The video follows specialists from a hospice who carry out holistic assessments and support the development of end-of-life care plans based on the wishes of the cared-for person.

### Activity 3

Allow about 40 minutes

Watch the video [End-of-life care: what matters to the person who's dying](#).

As you watched the video, did you spot how the cared-for persons are included in the decisions about their end-of-life care?

Make brief notes about the plans they made.

*Provide your answer...*

### Discussion

You might have noticed that the intervention by the specialist helped provide some clarity for the family of the first patient. The second patient was initially reluctant to make plans about her end-of-life care but, with the help of a social worker, she did make plans for her end-of-life care and felt more confident and in control because she felt supported.

The video emphasises that while we will all die one day, we also only get one chance to get end-of-life care right. It is therefore important to listen and to act on what the person says. This might include explaining what is happening to family members and others who are close to the person. In this way, talking about what a good death can mean to the person can enhance the quality of their life as they near death.



The palliative care specialists from the hospice were very confident in the way they interacted with the two women in the video. This confidence was due to them being very able to do their jobs in difficult situations, but was also down to their understanding that end-of-life care was primarily about the cared-for people. The development of their relationships with the women was built on a particular approach to their role: being person-centred and holistic. This approach was underpinned by principles that guided how they interacted with the two women. These principles are explained in more detail next.

## 4 Common core principles

[Skills for Care](#) and [Skills for Health](#) are two organisations that offer development and workforce learning in the health and social care sector under the umbrella of Skills for Care & Development. The other organisations are:

- [Care Council for Wales](#)
- [Northern Ireland Social Care \(NISCC\)](#)
- [Scottish Social Services Council \(SSSC\)](#).

Children and early years employers should contact [Skills for Care & Development](#).

These organisations acknowledge that while people nearing the end of their life often need specialist care and support, non-specialists who participate in social care and health care increasingly find themselves working with people who are dying. For instance, family carers and caregivers in residential homes for older people might care for people at the end of their lives.

You might have noted that palliative and end-of-life care encompass some important principles: being person-centred and holistic, for example. In the next activity you study the seven core principles (Skills for Health and Skills for Care, 2014) that underpin end-of-life care. These principles provide a framework for practitioners who deliver end-of-life care. Completing the activity will equip you with the necessary knowledge to understand the processes affecting people who are at the end of their lives.

### Activity 4

Allow about 25 minutes

Read the seven common core principles below.

When you have finished, make a brief note of how each principle might affect end-of-life care for an individual.

#### Principle 1

Care and support is planned and delivered in a person-centred way with the person's priorities, including spiritual, emotional and cultural needs, guiding all decisions and actions.

#### Principle 2

Communication is straightforward, appropriate and timely and is delivered sensitively, taking account of the circumstances, needs and abilities of the person and their carers. Communication reflects an understanding of, and respect for, the person's cultural and spiritual needs.

#### Principle 3

End-of-life care is provided through integrated working, with practitioners collaborating to ensure seamless care and support at the point of delivery. Needs are met in ways that are appropriate to the person, rather than being service-led. Workers maintain ongoing communication so that care and

support is properly coordinated and responsive to changing circumstances and priorities.

#### Principle 4

Good, clear and straightforward information is provided to people and their carers.

#### Principle 5

Regular reviews and effective communication ensure that care and support is responsive to the needs and changing circumstances of people, and their carers.

Forward planning, including advance care planning, facilitates well-coordinated, organised and delivered care and support.

#### Principle 6

The needs and rights of carers are recognised and acted upon. Carers are offered support both while caring and during bereavement. Employers recognise the ways in which workers are affected while caring for someone who is dying, and provide appropriate guidance and support.

#### Principle 7

Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to deal with people at the end-of-life. Workers are encouraged to take responsibility for their own learning.

(Source: Skills for Health & Skills for Care, 2014)

*Provide your answer...*

### Discussion

Briefly, the principles are:

1. person-centred care
2. communication
3. integrated working
4. information provision
5. planning and evaluation
6. rights for carers
7. proper preparation.

These principles reflect the skills that will enable you to provide care for the dying person that contributes to a good death.

So, how did you get on with identifying how the principles might affect the end-of-life care of an individual? Here are some brief notes that are possible answers to the activity question.

- Principle 1: The cared-for person chooses where to die – at home or in a hospital or hospice.
- Principle 2: The cared-for person is listened to carefully to find out their wishes and preferences.
- Principle 3: All the paid and unpaid carers talk to each other.
- Principle 4: Carers are open and honest with each other and the cared-for person.
- Principle 5: As needs change so does the care in response.
- Principle 6: Carers are cared for as well.
- Principle 7: Carers are trained and supported.

## 4.1 Holistic common assessment



Figure 1 A young woman holding the hand of an older woman

From what you have studied so far in this section, you will know that holistic and person-centred end-of-life care relies on understanding the dying person and their disease or illness. This depends on a good and detailed assessment that takes into account the person's wishes. In short, a good assessment of people's needs and preferences is more likely to lead to a good death than interventions that are based on assumptions about what an individual wants. The [holistic common assessment](#) (NHS National Cancer Action Team, 2010) is one tool that has been devised to meet the changing, complex and wide-ranging needs of people who are approaching death.

The holistic common assessment provides an opportunity to explore the individual's wider needs and identify how they might be met. By supporting choice and decision making the individual is able to identify what they want for themselves. By considering: Who? When? Where? and How? professionals are guided in delivering what the individual wants.

- Who should be assessed?  
The person who is recognised as moving towards the end of their life.
- When should they be assessed?  
Assessment should be seen as a continual process, where assessment is followed by reassessment.
- Where should the assessment take place?  
Anywhere that the person is comfortable and has privacy.
- How should assessment be carried out?  
The assessment should be conducted by a professional, who reviews previous assessments and aims for holistic care and potentially advanced care planning.

(Source: Extract adapted from NHS National Cancer Action Team, 2010)



## 5 Approaching death

One of the aims of end-of-life care is that the person has a good death. If possible, what constitutes a good death is decided by the person who is dying. You will now follow the case study about Frank and Grace. This case study has been divided into separate activities so that you can follow them as they prepare for Frank's death. In the first part you learn more about difficult conversations.

### Activity 5

Allow about 15 minutes

#### Part 1

Read an excerpt that has been adapted from *Finding the Words* from the National End of Life Care Programme (Department of Health, 2011). It is about the worries that people and carers might have at the end of their life.

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

- **Relationships** Am I still needed as a partner/parent/son/daughter or 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?  
Do I really believe I am going to die?
- **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?

(Source: Department of Health, 2011)

## Part 2

Now read the case study about Frank and Grace and answer the questions that follow.

### Case study: Frank and Grace Taylor



Figure 2 Frank and Grace embrace

Frank (64) and Grace Taylor (62) are very close. They have been married for over forty years. Frank is a retired civil engineer who has been receiving palliative care for bowel cancer for over a year. He is now receiving end-of-life care. He has secondary tumours throughout his body. There is little record of his health conditions prior to his diagnosis as he rarely visited his GP. He liked meat-based meals and drank spirits moderately at the weekend. Grace has been treated for depression recently.

Over the last month Frank has gradually grown weaker. Grace is adamant that she wants to be fully involved in his care. There has been much in-depth discussion of his approaching death. The time for a 'difficult conversation' has come to find out from Frank and Grace what is important to them towards the end of life.

For Frank an advanced care plan aimed to keep him at home in line with his and Grace's wishes. He was helped with personal care by carers from a local agency, and a community/home nurse visited daily to tend to the more technical elements of his care including medicines management.

1. What sorts of thing would you want to discuss with someone facing the end of their life?
2. How would you approach Frank and Grace about these matters?

*Provide your answer...*

### Discussion

There are some questions that are appropriate for the person whose life is ending and other questions that should be asked of their family or friends. Asking questions of other people might provide you with information that would enable you to give good-quality person-centred care; that is, care that the person near death deems to be good quality. Sometimes it might be difficult for people or their relatives to tell you what matters to them. Being sensitive, genuine and compassionate are vital at such times.

## 5.1 Advanced care plans

An advanced care plan is a structured discussion with patients and their families or carers about their wishes and thoughts for the future. It enables:

- better planning and provision of care to help them live and die in the place and the manner of their choosing
- clarification of people's wishes, needs and preferences
- delivery of care to meet these wishes, needs and preferences
- important yet simple conversations that can change practice and empower patients
- in-depth communication between patients and their families and loved ones.

(Source: adapted from Gold Standards Framework Centre, 2015)

Enabling advanced care planning is one intervention you can make with Frank and Grace. However, not all situations that occur can be planned for. One example is pressure sores or ulceration. Sometimes in end-of-life care the development of pressure sores is difficult to avoid due to skin changes that accompany ageing, failure of the circulatory system and disease progression. There are measures, though, that can be taken to protect and treat areas that are particularly vulnerable to ulceration. This is the case with Frank.

## 5.2 Signs that death is near

In the next activity you will continue to follow Frank and Grace in his last days. The National Council for Palliative Care website has a page on [Signs that death is near](#). Being able to recognise these signs can help relatives and others close to the person to prepare for what is to come and to say goodbye.

### Activity 6

Allow about 10 minutes

#### Part 1

Read the National Council for Palliative Care list of indications that someone is approaching death.

As death approaches, you may see some or all of the following changes:

- **Physical changes**

In older people the skin can become paper-thin and pale, with dark liver spots appearing on hands, feet and face. Hair can also thin and the person may shrink in stature. Teeth can discolour or develop dark stains.



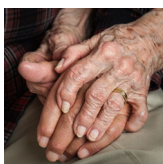


Figure 3 Hands can show physical changes as people age

- **Shrinking world**

The person's external world begins to diminish until the dying person no longer wants to leave the house or their bed and may not want to talk very much. Their mood, character and behaviour may change. For example, some may become more anxious. Others who have held atheist views may suddenly want to explore religious or spiritual teachings.

- **Increased sleep**

The person begins to sleep for long periods. This can be distressing for relatives, but it's important to understand that even the mildest physical exertion for someone approaching death can be exhausting, and for the moment all effort is being put into staying alive. Nearer the end, the dying person may increasingly drift in and out of consciousness.

- **Appetite reduction**

Appetite reduces as the body knows it no longer needs fuel to keep it going so those who are dying often lose their desire to eat or drink. They can begin to lose weight, sometimes rapidly. It's important not to force food or drink onto someone who no longer wants it.

- **Expression**

There may be changes of expression where the person may start to talk about 'leaving', 'flying', 'going home', 'being taken home', 'being collected', 'going on holiday' or making some kind of journey. They may also begin to express heart-felt gratitude to their carers and to their family as a preparation to saying their farewells.

- **Special requests**

The person might make special requests, such as asking for something special, wanting to visit a particular place, or wishing to be surrounded by their favourite flowers. They may want to hear certain music, to have family photographs nearby or to make contact with someone who has been important in their lives. Some special requests might be difficult to fulfil, especially if they are unusual or illegal such as the choice of disposal of the body. It would be helpful to discuss unusual or illegal requests with a professional who might be able to clarify what can be done, and what alternatives might be considered.



Figure 4 Those being cared for may request to see family photographs

## Part 2

Read about Frank's last days before answering the questions that follow.

### Case study: Frank and Grace

Frank now prefers to stay in his bed most of the time where he is most comfortable. He has carers visiting three times a day to provide personal care. It includes repositioning him to avoid damaging tissue at pressure areas. His physical comfort has been given priority. At one stage it was thought he was retaining urine but since then he has been incontinent several times. He has also appeared to be in pain and has groaned in his sleep while trying to move.

As swallowing was obviously difficult for Frank, a syringe driver became necessary to ensure his morphine-based pain relief is effective. During a regular check on vulnerable areas it is revealed that the skin at the bottom of his spine is looking red and very dry. Grace feels guilty about this as she has always observed and monitored the carers adjusting Frank's position in bed.

Frank had been in bed for eight days. During this time Grace was vigilant for any deterioration in his condition. His medication was increased so that he was drowsy most of the time. He drifted in and out of consciousness. When Frank woke for a few minutes he appeared disorientated and Grace was not sure that he knew who she was. He mumbled but his speech was slurred and unclear so Grace could not understand what he was saying.

He did, though, appear to be looking at something. She observed that the periods of unconsciousness were more prolonged. Frank's respirations were shallow and he sounded chesty. Holding his hand, Grace noticed that he was cold. By the time of his death, Frank had been unconscious for twenty-four hours. He had not taken any fluids or other nutrition during this time.

- In what ways did Frank show signs that his death was near?

Reread the indications and the case study if you need to, and make some notes in the box below.

*Provide your answer...*

### Discussion

Being most comfortable in bed is one sign that Frank might be near to death. Recognising signs of death can help make his last days and hours as comfortable as possible.

Many of the items in 'Signs that death is near' are reflected in what Frank and Grace experience. You would have been aware of some of the physical changes: Frank's skin, for example, and the shrinking of his world.

Frank slept more but this might have been as much to do with his medication as impending death. His appetite was probably reduced. Being drowsy, to feed him might have entailed further physical interventions that would make him less comfortable.

Frank seemed to have had no special requests at the last moments, although we cannot be certain. He appeared to want to say something. His change of expression, looking for something, might suggest a desire to make a special request.

## Key points from Section 3

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In this section you have learned:

- what palliative and end-of-life care are
- how palliative and end-of-life care can contribute to a good death
- ways to improve a person's quality of life as death draws near
- how someone can be supported to have a good death
- to recognise signs of approaching death.

Section 4 explores positive risk-taking. Risk assessment is usually considered to be solely about minimising risk to others. Studying this section will show you that positive risk-taking can bring additional benefits when the needs and preferences of the cared-for-person are taken into account.

## Section 3 quiz

Well done; you have now reached the end of Section 3 of *Caring for adults*, and it is time to attempt the assessment questions. This is designed to be a fun activity to help consolidate your learning.

There are only five questions, and if you get at least four correct answers you will be able to pass the quiz.

- I would like to try the [Section 3 quiz](#).

If you are studying this course using one of the alternative formats, please note that you will need to go online to take this quiz.

## I've finished this section. What next?

You can now choose to move on to Section 4, Positive risk-taking, or to one of the other sections.

If you feel that you've now got what you need from the course and don't wish to attempt the quiz, please visit the [Taking my learning further](#) section. There you can reflect on what you have learned and find suggestions of further learning opportunities.

We would love to know what you thought of the course and how you plan to use what you have learned. Your feedback is anonymous and will help us to improve the courses that we offer.

- Take our [Open University end-of-course survey](#).



# Positive risk-taking

## Introduction

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Risk is a necessary and important part of life for all of us but we need to think about and manage this risk. In this section you will be looking at risk in relation to cared-for people. The cared-for person has the right to take risks. When managing risk, however, there is the potential for carers to be cautious with an emphasis on overprotecting the cared-for person. In this section you will be exploring how carers can continue to empower the person they are supporting to have a more fulfilling life – in particular, through positive risk-taking.

Here we suggest that positive risk-taking can bring real benefits when it takes into account the needs and preferences of the cared-for person, the rights and responsibilities of their carers and the specific circumstances. The cared-for person is enabled to grow in confidence, learn from their experiences, develop new skills and abilities, or maintain the ones they already possess, and make full use of their opportunities and potential.

The course team acknowledges that there can be challenges with positive risk-taking. Paid care workers might feel more constrained than informal carers when it comes to positive risk-taking. Their employer might restrict what they would wish to do. At the same time, the informal carer might not be aware of the opportunities that could enhance the life of the cared-for person if they are encouraged to take positive risks.

You begin your study by looking at mental capacity. You then examine how independence can be encouraged and nurtured, followed by learning how carers can adopt the least restrictive practice (which means allowing the cared-for person to do the things they can still do) when considering risk to individuals. In the last topic you reflect on what happens when the cared-for person's carer is unavailable and an emergency care plan is required. At the end of the section there is a short quiz to test what you have learned about positive risk-taking. On successful completion of the quiz you will earn a digital badge.

This section is divided into four topics and each of these should take you around half an hour to study and complete. The topics are as follows:

1. **Mental capacity** is explained and you learn about how capacity is assessed and the role carers might have in dealing with capacity.
2. **Promoting independence** is about supporting people to reach their full potential and to be able to do as much as they can for themselves.
3. **Least restrictive practice** is about ways to support people to enjoy independence and life-enhancing activities in the safest possible way.
4. **Emergency care plans** are discussed in relation to why they are necessary and the type of essential information required.

# Learning Outcomes

By completing this section and the associated quiz, you will be able to:

- understand why positive risk-taking is important as a means to enable cared-for people to have a more fulfilling life
- understand how carers can balance positive risk-taking while providing safe care to the cared-for person.

## 1 Mental capacity

The law says you have to start from the position that everyone has the capacity to make decisions about their lives. Some people are born with limited capacity: through brain damage, for example. Other people lose their capacity to understand information and make decisions about themselves through accident, ill-health or a degenerative ageing process.

To better understand how capacity relates to the caring role, you first look at what capacity is and how it might affect a cared-for person. You go on to learn about how capacity is assessed and then how the caring role might be affected by the cared-for person's capacity. Your learning from this topic will help you to appreciate how mental capacity and positive risk-taking are linked. For the cared-for person, having the mental capacity to make decisions is an important element in being able to judge exposure to risk.

### Activity 1

Allow about 10 minutes

Reflect on what you know about dementia or another serious health condition, such as a stroke, and make a list of the ways that the cared-for person's mental capacity might be affected.

*Provide your answer...*

### Discussion

A feature of dementia is that the person gradually loses their ability over a period of time to remember and think clearly. Some health conditions such as cardiovascular accidents (strokes) can have the same effect. This, of course, can mean that a person's ability to understand information and make decisions based on that information is impeded. Mental capacity might affect a cared-for person in a number of ways: for example, they are no longer able to manage their financial affairs, or decide on what to eat or which clothes to wear that are appropriate to the weather.

How capacity is determined is governed by law. The relevant law in Scotland is the Adults with Incapacity (Scotland) Act 2000. At the time of writing, the Northern Ireland Assembly is considering a Mental Capacity Bill. In England and Wales, the Mental Capacity Act



2005 is the primary legislation that sets out what capacity is and how an individual's capacity is managed.

Crucially, the Mental Capacity Act states that a person lacks capacity if they are unable to make a decision for themselves in relation to a *specific matter* at a *particular time*. It acknowledges that the ability to make decisions can change with circumstances. For example, if a person lacks capacity to manage their financial affairs at one time, it should not be automatically assumed that they lack capacity to manage their financial affairs ever again.

A person's capacity may be permanently affected due to dementia, a learning disability or brain injury. However, it is not associated with any particular condition and is dependent on an assessment being made before any decision about capacity is made. Capacity might also be temporary. An older person might become temporarily confused due to a urinary tract infection, for instance, but then receive treatment and recover and regain their ability to make informed decisions.

In the next part you learn more about the Mental Capacity Act 2005 and how it might protect the cared-for person.

## 1.1 The Mental Capacity Act 2005

The Mental Capacity Act 2005 details certain principles or guidance by which capacity should be assessed. It states how managing a cared-for person's capacity must be carried out.

These principles are summarised below.

- Capacity must be assumed, unless a lack of capacity is established (i.e. the starting point is to assume that someone is able to make decisions).
- A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because they make an unwise decision.
- Any decisions or actions made related to capacity must be in the cared-for person's best interests.
- Any decisions or actions taken related to capacity must be achieved in a way that is least restrictive of the person's rights and freedom of action. (You learn more about least restrictive practice later in this section.)

### Activity 2

Allow about 10 minutes

To help you understand how the principles are applied, read the brief case study below. Would you conclude that the person at the centre of the case study, Desmond, has capacity or lacks capacity?

#### Case study: Desmond

While out shopping, Desmond collected his pension and gave half to a *Big Issue* seller. He then found and wore a colourful hat, which he wore to the supermarket

where he bought some processed food and enjoyed a strong coffee with four sugars.

Later that day, a neighbour told Desmond's daughter that he should not be allowed out by himself as he had made a fool of himself and clearly was unable to look after himself properly.

*Provide your answer...*

### Discussion

It seems that the neighbour who witnessed Desmond's behaviour earlier that day assumed he was not able to look after himself as he should. You might argue about how wise Desmond's decisions were, but they do not necessarily demonstrate lack of capacity to make decisions. At this stage, no attempt had been made to ascertain if Desmond was able to understand any concerns about his behaviour, retain information about any concerns, think through why his neighbour was concerned or communicate his own views on what he was doing.

Placing restrictions on Desmond's trips to town would not necessarily be acting in his best interests as it would deprive him of the opportunity to act independently and stop him doing what he wanted. If his daughter and others continued to have concerns about Desmond's behaviour they could ask for an assessment of his capacity.

You learn more about assessing capacity in the next activity.

## Activity 3

Allow about 20 minutes

Read the case study and then answer the questions that follow.

### Scenario

Imagine that your friend Kevin calls round to ask you to help him take his wife, Caroline, to hospital for an appointment at a memory clinic. He says that Caroline is now objecting to going to the hospital and Kevin feels that if you accompanied them she is more likely to go. When you meet Caroline at their house you find that Kevin has already taken the car out of the garage. He recounts how he helped Caroline wash, and choose appropriate clothing and dress, saying that in each of these activities he reminded her about her appointment at the memory clinic.

Kevin reminds Caroline again as he helps her put on her shoes and a coat. You note how he gently reminds her about going to the hospital and how long it will take. You suggest that they might go for a coffee afterwards.

1. In what ways do you think Caroline's capacity might be affected?

*Provide your answer...*

### Discussion

As the appointment is at a memory clinic, it is likely that Caroline is experiencing memory problems. If she has difficulty with her short-term memory she may be unable to retain information about the hospital appointment. Caroline's ability to understand that she has the hospital appointment and why she has the appointment is probably impeded, and she may object to going to the hospital clinic.

2. What support might you offer Kevin?

*Provide your answer...*

### Discussion

You could note how Kevin patiently takes practicable steps to help Caroline understand and attend the appointment. For example, Kevin repeats the information about the hospital appointment several times. It might be that you can repeat to Caroline the information Kevin has already given her and hold her hand, perhaps while Kevin prepares to get in the car. Comforting words, perhaps, would help reassure Caroline that where she is going is in her best interests.

## 1.2 Assessing mental capacity

When assessing someone's mental capacity, in the first instance you should always presume a cared-for person has sufficient understanding or mental capacity to make decisions. Only when there is real doubt about the cared-for person's capacity to make a decision in a particular situation should an assessment be made and, only after the assessment has concluded that the person lacks capacity, can decisions be made for them. Before deciding that someone lacks the capacity to understand information and make decisions, you should first establish if the person can be supported in making their own decisions.

Questions you could ask are:

- Does the person have any mental impairment?
- Are there any signs or symptoms of disability, illness or cognitive decline?

If yes, further questions are:

- Should these issues be assessed and treated before lack of capacity is determined?
- Does the impairment or disability prevent the person from making the decision?  
Being ill, disabled or mentally impaired does not automatically lead to a lack of mental capacity.

In many circumstances, such as everyday decisions, the carer might be the best person to answer these questions. However, for some decisions a person's mental capacity needs to be assessed and this would be the responsibility of professionals such as a social worker or a doctor. In these circumstances, every effort to help the person to understand the information and to make a decision must be made before judging that the person can or cannot make their own decisions.

## 1.3 Mental capacity and decision making

If the cared-for person lacks capacity to make a decision, then someone else might have to make the decision on their behalf. Very often it is the carer who accepts this responsibility. However, there are times when the responsibility does not lie with the carer.

Some decisions about social care services that require funding or treatment for a health condition are normally made by a health or social care professional. However, although this type of decision is outside the responsibility of the carer, the carer should still be consulted and asked for advice as they will usually know the cared-for person best.

The law says that any decisions must be made in the 'best interests' of the cared-for person. This means taking all the relevant factors into account, including:

- consulting the carer and any other family members and close friends
- involving the cared-for person as much as possible and listening to what they say
- taking into account the cared-for person's past opinions, values and beliefs
- restricting the person's freedom as little as possible.

When the carer is asked to help, it is important that their opinions are taken into account. You can do this by listening to them and remembering that they often have a better understanding of the cared-for person than anyone else.

## 2 Promoting independence

To promote independence means to support a person to reach their full potential and really do as much as they can for themselves.

This topic will help you to recognise that the concept of independence varies from person to person and to appreciate the impact independence can have on everyday life.

A valued life is one where a person is given respect, dignity and privacy and is supported to make their own choices about what happens to them. This topic will help you to understand this, so you can support the people you care for with a better awareness of the role positive risk-taking can play in helping them in gaining or retaining their independence.

The Care Act, which came into force in England in April 2015, replaced most of the current law regarding carers and people being cared for, and put new obligations on local authorities. One of these is a general duty to promote an individual's well-being. This means that they should always have people's well-being in mind when they make decisions about them or plan services. The term 'well-being' includes:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional well-being
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support)
- participation in work, education, training or recreation
- social and economic well-being
- domestic, family and personal relationships
- suitability of living accommodation
- the individual's contribution to society.

Local authorities have to consider the impact of your role as a carer on your well-being. Similarly, they have to consider the impact of a disabled person's needs on their well-being.

In Wales, the Social Services and Well-being (Wales) Act 2014 came into force in April 2016. The definition of wellbeing is broadly the same as that covered in the Care Act in England.

Definition of well-being from the Social Services and Well-being (Wales) Act 2014:

- a. physical and mental health and emotional well-being
- b. protection from abuse and neglect
- c. education, training and recreation
- d. domestic, family and personal relationships.

(Source: Wales. Social Services and Well-being (Wales) Act 2014, p. 13)

But, unlike the English Care Act, it also covers certain aspects of legislation relating to children.

In a paper published by Scope, [Our Support, Our Lives](#) (Davies, 2015), about the right to independent living, we are told that social care is about more than just the basics and must enable disabled people to live fully independent lives, putting them at the centre of

their own care. This concept applies to anyone receiving care, not just people with disabilities, and Scope says that this is the key to being able to achieve the well-being principles outlined in the Care Act.

Whilst this report related to services in England, the principles of the report are also applicable to Wales.

This link from Disability Wales may also be useful:

<http://www.disabilitywales.org/social-model/independent-living/>

#### Activity 4

Allow about 10 minutes

What does independence mean to you?

Think about this statement, and write a sentence below about what independence means to you.

*Provide your answer...*

#### Discussion

Most definitions of independence say something like 'the ability to live your life without being helped or influenced by other people' (Cambridge Dictionaries online, 2016).

Now think about this:

If you lost your independence, what would you miss most?

Write down the three things you would miss most if you lost your independence.

*Provide your answer...*

#### Discussion

When you answered the question you might have thought about what would affect you most by losing your independence and who else it would affect, e.g. husband/wife/mum/dad/other family members.

Do you think you would feel isolated, powerless, like a child or a baby again?

You may also have considered what you would miss doing the most. There are lots of everyday activities that we take for granted, like being able to get up and get ready for the day when we want or need to. Or being able to choose how we spend our leisure time.

Think about how the loss of independence could make someone feel, coupled with being separated or cut off from the rest of society – the effect could be devastating.



Figure 1 What independence means to people with disabilities or conditions that make them dependent on others

The quotes in Figure 1 are from a Customer Action Network meeting at Leonard Cheshire Disability when participants were asked what independence meant to them. These are things that most of us take completely for granted, but for people living with disabilities or other conditions that make them dependent on others, that is how they define independence.

Look at what [someone with a significant disability](#) can achieve with the right support. Ray De Grussa mastered using specialist computer software to achieve his ambition of composing music. He received an award at Adult Learners' Week in 2012 but his real reward was that he was finally enabled to achieve his ambition.

## 2.1 Care or support – what's the difference?

There's a subtle but very important distinction between caring for someone and supporting them, which can mean the difference between being just 'OK' and living to their full potential.

### Caring for someone

Although we use the term 'caring for someone' throughout this course, and it is the most widely used term for looking after someone, the simplest care involves helping someone in their daily needs. An example of simply caring for someone would be 'Would you like a cup of tea?' to which the reply is 'Yes'. The carer then makes and hands the individual a cup of tea. On the face of it, this looks like good care but what part does the cared-for person play in this task?

### Supporting someone



Figure 2 Supporting a person to feed herself

If 'caring for someone' is the minimum standard, 'supporting someone' goes to the next level. It is about empowering people to take more control over even the smallest things in their lives *or even a small part of a small thing*; things that most of us would take for

granted. Basically, it's about seeing every 'care need' as an opportunity to help the person you care for to make choices, develop skills and be more involved in creating their own outcomes. This should be a gradual process, supporting the person bit by bit to lead a more fulfilled life.

Let's go back to our example of the cup of tea. You have asked 'Would you like a cup of tea?' and the reply was 'Yes'. The extra step is supporting the individual to complete as many of the stages of making the tea for themselves that they are able to. They may only be able to put the tea bag in the cup but that is a start. Maybe they could also switch on the kettle and get the milk from the fridge in time. Yes, it will take longer but will be much more rewarding for the individual than just being given a cup of tea. It is true that it may be a nice thing to make someone a cup of tea but not if they never have the opportunity to make one for you.

## Why the distinction is important

Without supporting the people we care for to become empowered there are few chances for them to continuously develop in all aspects of their life. By supporting them in even the smallest tasks, they make progress every day – it might be two steps forward, one step back, or only happen over a long period of time, but the important thing is they *are* making progress.

In terms of care provision it is important because it is the 'harder' path to take for staff and caregivers. It involves more patience, more thought, more involvement and more time. But becoming more involved in someone's development engages carers more, and it is rewarding to see the person you care for achieve something new or be able to do something they were able to do when less care was needed. It gives better outcomes for both staff and carers and the people they are supporting.

As carers we tend to do things for the people we support as we underestimate their abilities or because it is quicker. But do you want to make life too easy for the people you support, with too many 'get outs'? Why would they make the effort if you do it all?

This approach can lead to you telling the people you support what should happen rather than giving them the choice. Isn't this the way that we treat our children until they start creating and living their own lives? And those who can't communicate in the same way can become trapped and will often find another way to rebel in their desire for individuality. This can express itself as challenging or anti-social behaviour.

### Activity 5

Allow about 10 minutes

Read the case study below and put yourself in Betty's shoes. Then answer the questions that follow.



## Case study: Betty



Figure 3 Betty

Betty is a widow in her 70s who lived independently until she had a stroke recently. She has made a good recovery of her speech and cognitive skills but has lost the use of her right arm and is unsteady on her legs. Betty has family but none of them live close by and she receives support from a private home care service.

Betty gets frustrated at not being able to do all the things she used to, and feels the carer doesn't have time to listen to her and find out what she needs: 'She just carries out her tasks and goes off to the next customer'.

- How would you feel if you were Betty?
- How could the carer enable Betty to be more independent and do the things she wants in life?

*Provide your answer...*

### Discussion

Betty has already said that she thinks the carer doesn't have time to listen so she may feel that she is being 'a nuisance'. But other feelings may include frustration at having to be reliant on other people – she may be angry that this has happened to her. Betty has always been independent, so she may also be angry at herself because she can't do everything she used to do.

The carer could take some time to find out about Betty's feelings and the way she would like to be supported. They could work on a care plan so that anyone supporting Betty would know how she would like to be treated, and what is important to her and for her to enable her to have a good day.

By allowing Betty to do the parts of tasks she can manage for herself, she would feel more independent and less reliant on others.

## 2.2 People or technology?

Some disability charities, such as [Sue Ryder](#), offer 're-ablement' programmes that aim to help people who live with degenerative conditions, such as multiple sclerosis, or who have had strokes. Programmes such as this offer practical help and assistance to meet the specific needs of each participant.

Organisations like [Reablement UK](#) also offer training and support to care staff, giving them the knowledge and skills to work with people to regain their self-care skills and become as independent as possible.

However, the majority of re-ablement in Wales is done through local authorities and health boards. This report may be of interest in this area:

[http://www.royalvoluntaryservice.org.uk/Uploads/Documents/Reports%20and%20Re-views/getting\\_back\\_on\\_your\\_feet\\_reablement\\_in\\_wales\\_report.pdf](http://www.royalvoluntaryservice.org.uk/Uploads/Documents/Reports%20and%20Re-views/getting_back_on_your_feet_reablement_in_wales_report.pdf)

## Definitions of assistive technology

There is confusion and misunderstanding of the term ‘assistive technology’ at all levels – and this is not surprising. The technology is developing so fast that even the health professionals responsible for prescribing assistive technology will openly admit they are unaware of what is currently on the market.

However, there have been attempts to try to define assistive technology and what it can do. Here are two: the first is taken from the sales literature of RSLSteeper, a company that provides assistive technology equipment:

Assistive Technology is any device that helps a less able person do something that more able people can already do.

(Source: AZO Robotics, 2016)

The second definition is from a user group consultation at the King’s Fund in 2001:

Assistive Technology (AT) is any product or service designed to enable independence for disabled and older people.

(Source: King’s Fund, 2001)

Although these definitions are accurate, they don’t really help to explain the vast array of technology out there, the different purposes of it or what it needs in order to work effectively.

What we do know is that assistive technology can have a huge positive impact on someone’s life, as you will see from the following case study.

## Case study: Beverley Glover



Figure 4 Beverley Glover and her technology

Beverley Glover is a great fan of assistive technology. She uses her device to open her doors, windows, curtains, raise and lower her bed, control her TV, DVD and fan, make calls to her daughters and, at Christmas, uses her lamp control to switch on her Christmas tree lights!

She also uses a communication device when she is out and about, which helps people to understand her.

Bev bought her equipment independently, but she was assessed by a specialist regional service in the north west who now provide her equipment, maintain it for her and add on bits of electrical equipment when she needs it – all for free.

## Types of assistive technology

Assistive technology can be categorised in three ways:

- **Augmentative or alternative communication** This refers to processes and tools to aid one-to-one communication; for example, everything from communications passbooks (explaining a person's background and preferences) through to a 'grid' (a Perspex board with words bordering a clear space so that the recipient can see

which word the user is looking at) to electronic devices that speak for the person (Primo).

- **Communication assistive technology** For people with impaired speech, such as those living with conditions like cerebral palsy, autism or a stroke, speech generation devices can help to enhance their existing capabilities or give a voice where speech is severely impaired.
- **Environmental assistive technology** These technologies assist a person to engage with their living space, and can open and close doors and windows, curtains and blinds. It can turn lights on and off, and control heating as well as home entertainment. The technology can also answer and make phone calls, activate alarm or nurse calls, and control the functions of a bed.

## How does assistive technology work?

As long as a piece of equipment has either an infrared or a radio signal in an independent living environment, the device can be used by someone with disability. Simply controlled devices such as table lamps can be converted by an adapted plug, which is then controlled by an infrared signal.

In the case of doors, windows, curtains, blinds and light fittings, the most satisfactory way of incorporating the technology is during the building of a property.

Devices can be fitted retrospectively, and while the additional wiring on the walls may not look very attractive, it is better to have the technology than not.

**Note:** Environmental technology that affects the building will not be funded by NHS assistive technology providers. In the case of supported living, however, depending on location, Social Services may assess the living environment and make adaptations to suit the needs of the patient.

Gaining access to equipment is achieved through a control device in the same way that an able-bodied person would turn on the TV with a remote control. What access is easiest for the individual will determine the type of control device and switch prescribed. When people say that assistive technology doesn't work for them, access will usually be the problem. For example, the door or window will open and close remotely but the means to open it for that person has not been assessed correctly and is causing problems.

There are many, many controls and switches on the market and consequently choice can be daunting. People choosing assistive devices will need to take into account their condition and whether it is likely to deteriorate, to ensure that the chosen device is the most appropriate one for them.

The next activity will start you thinking about the benefits of assistive technology.

### Activity 6

Allow about 5 minutes

Read the case study below and then answer the question that follows.

#### Case study: Ray Grocott and his Freeway machine

Ray Grocott lives in a Leonard Cheshire Disability residential service. Figure 5 shows Ray and his wife Diane, and Ray's Freeway machine. Ray uses a Freeway

device, which allows him to, for example, turn on lights, lamp, TV and radio, and to open doors and windows that are connected to his Freeway. As he is unable to hold the device, he can use a switch that can be activated by whatever movement the individual is capable of, such as head, chin, finger, foot and so on.



Figure 5 Ray and Diane, and the Possum Freeway 2

Diane realised the power of the technology when she was on the phone to Ray one evening. She told him, 'There's a great programme on BBC1'. But as she began to explain it to Ray she was interrupted by a voice in the background, 'Are you ready, Ray..., Lamp..., BBC1' and they were able to watch the programme together.

Diane travels a lot for work and listens to audio books. She now shares her audio books with Ray who can access them when he wants. This has given them new topics for conversation.

Ray goes home at the weekends. North West Assistive Technology, their NHS assistive technology provider, has duplicated Ray's system in his own home. When he wakes in the night he can turn on his light and the TV without breaking Diane's sleep, which makes life so much better for Diane.

Diane said: 'The Possum Freeway 2 has changed Ray's life. To lose it now would be like him losing another ability.'

And Val Kirk, Assistant Therapist at Hill House (the Leonard Cheshire Disability care home), said: 'Being empowered to take back independence which has been robbed from individuals by debilitating illness has improved their whole well-being.'

How do you think assistive technology has benefited Ray and his wife?

*Provide your answer...*

### Discussion

You may have thought about the following:

- The technology has increased Ray's independence, giving him more control over his life.
- It has enhanced Ray and Diane's relationship as it enables them to share activities and gives them more to talk about.
- As the technology has been duplicated in his home, Ray can be independent at home and this in turn enhances Diane's life by giving her a better night's sleep.

## 3 Least restrictive practice

What have you done today that could be considered risky? You might have driven a car, crossed a road, made a cup of tea, taken the dog for a walk ...



(a) A woman getting into a taxi before it drives off (b) Crossing a busy road



(c) Making a cup of tea has potential risks of both electricity and scalding (d) Taking a dog for a walk

Figure 6 Risky activities?

- Do you know what risks you are taking every day?
- If someone suddenly told you that you aren't allowed to drive because of the risks involved, what would you say?
- If you never took a risk what would happen? Would you grow as a person?
- Do you think of risk as positive or negative?

Often risks are associated with injury, loss, danger, damage or threat, and if a risk is perceived negatively, it can be used as an excuse to prevent people from doing something.

For example, some people may think that direct payments and personal budgets could put people more at risk of abuse and exploitation; others may feel they reduce risk by giving people greater control over their lives.

Taking risks is an everyday part of life – and life without risks would be very dull indeed. While it is important to try to identify risks in advance and reduce the likelihood of them happening, this shouldn't be an excuse for preventing people from having choice and control over their lives.

Do you like to have a drink in the pub or to go for a meal with friends? It's an opportunity to socialise and catch up with people, which is important to us for all sorts of different reasons. But you may have also been told that you need to lose weight, or you need to cut down on the amount of alcohol consumed as you are drinking more than the recommended limits than is good for you. You can weigh that up and make a choice – do you go to the pub/restaurant or do you stay at home and eat a healthy meal?

If that choice was taken away from you, how would you feel?

There has to be a balance and you need to ensure that you do not prevent someone you care for from having the right to do something simply because you do not believe it is good for them. You need to empower people and help them to access opportunities and take chances – and be positive about potential risks.

If you try to prevent people from doing anything that could be regarded as dangerous, you could potentially be preventing somebody from doing something they have the right to do.



Sometimes it can be difficult for carers to know where the boundaries lie in terms of what they can/can't or should/shouldn't do. In the next activity you will look at an example, and write down what you think your responsibilities would be in relation to your care of Sheila.

## Activity 7

Allow about 10 minutes

Read the scenario below and then answer the questions that follow.

### Scenario

Imagine you work in a residential home, and one of the people you support is Sheila. Sheila has diabetes, which she manages through her diet. One of the things that this means is that she has to limit the amount of sugar that she eats as eating too much sugar can make her become unwell very quickly.

Sheila really enjoys going to the local shops: she likes to buy sweets and cans of cola and often eats and drinks more than she should, which makes her unwell. The people who support Sheila are worried about her health but when they try to talk to her about their worries she says, 'It's my choice'.

- What are the staff's core responsibilities in supporting Sheila?
- What things might they try to better support Sheila?

*Provide your answer...*

### Discussion

The core responsibilities of staff would include:

- providing advice about diet
- supporting Sheila to make an informed choice
- supporting Sheila to access a dietician
- making sure that healthy choices are available for Sheila at meal times.

Ideas of what the staff might try to include in supporting Sheila is to look at alternatives; e.g. diabetic sweets, sugar-free drinks and giving her more information about her condition so that she can make better choices.

What the staff *cannot* do is:

- stop Sheila from buying cola and sweets
- take away Sheila's cola and sweets or stop her eating them
- make Sheila choose the healthy choice on offer.

## 3.1 Deprivation of liberty and restrictions

To start you thinking more widely about this topic and what it means for carers, take a look at this video about Tim and his desire for fish and chips.

Video content is not available in this format.

Working in an empowering way – fish and chips

### Scenario Five

“Fish 'n chips, they just hit the right spot”



The Deprivation of Liberty Safeguards (DoLS) are part of the [Mental Capacity Act 2005](#). They aim to make sure that cared-for people are looked after in a way that does not restrict their freedom more than necessary. The safeguards should ensure that this is only done when it is in the best interests of the person and there is no other way to look after them.

A recent court decision has provided a definition of what is meant by the term ‘deprivation of liberty’. A deprivation of liberty occurs when ‘the person is under continuous supervision and control and is not free to leave, and the person lacks capacity to consent to these arrangements’.

(Source: Alzheimer’s Society, 2016)

Any type of restriction applied within a care setting (including the person’s home) must be risk assessed and consent gained for the specific act. If someone doesn’t have capacity, and arrangements are made on their behalf, the ‘least restrictive option’ should always be



chosen, especially if the restrictions used mean that carers have 'complete and effective control' as this could constitute a deprivation of the person's liberty.

### Activity 8

Allow about 10 minutes

Read this [article from the Daily Mail](#) (2012), which gives an example of how the Deprivation of Liberty Safeguards were used to 'overprotect' somebody.

*Provide your answer...*

### Discussion

Although the person in question had dementia, it could not be proved that she was unable to make a decision about going on holiday.

The couple had been on many cruises in the last 20 years, so she would have an understanding of what the decision was about.

The council had been more concerned with finding ways to prevent her going on a cruise than with finding ways to make it possible.

## 3.2 The search for the least restrictive option

When professionals talk about using the 'least restrictive option' for cared-for people, some people think this means letting the person do whatever they want, even if it puts them at risk. The use of the least restrictive option applies only if the people you are caring for are considered to lack capacity under the Mental Capacity Act and should be used only if there is no better way to carry out the task. All people providing care should be comfortable with assessing capacity, but remember that just because someone makes a decision that others think is unwise, it doesn't mean that they lack capacity – we all sometimes do unwise things even when we have capacity!

Capacity is what's called 'decision-specific and time-specific': can the person make this decision at the time it needs to be made? The law says that we must do everything possible to enhance an individual's ability to make their own decisions.

### Activity 9

Allow about 10 minutes

Read about Johnny and then decide in which areas of his life he needs support with decision making.

### Case study: Johnny

Johnny lives in a residential home.

- He likes to wear his Manchester United kit when the team is playing.

- Johnny's family have warned his support workers that when he is particularly anxious, he will try to go to major roads to look at lorries: he has been brought back from the motorway hard shoulder on several occasions.
- Johnny gets worried and anxious when he needs to go to the doctor or nurse.
- If he gets anxious Johnny can't listen properly, which makes it hard for him to make decisions.

How can Johnny be supported? Write your thoughts in the space below.

*Provide your answer...*

### Discussion

People who care for Johnny could look for ways to improve his ability to make some decisions. They could perhaps ask his family for some tips on how to do this.

They could also find out more about what makes Johnny anxious, and particularly too anxious to listen properly. It will probably help to give him as much time as possible to make big or anxiety-producing decisions, and to repeat information in different ways, for example, by using pictures.

For little decisions, such as wearing his football strip, there is no reason to think that Johnny lacks capacity: he wears it when his team is playing. Even if he didn't have capacity, there is no risk associated with this choice, so it should be respected and praised: it's good to make choices and he is doing so.

Staff who support Johnny need to assess his capacity to understand the risk of going near major, busy roads. Maybe he cannot, for example, remember that the traffic goes really fast and may come on to the hard shoulder, or maybe he can remember this information but Johnny can't use it to decide not to go to the motorway.

If the staff decide he lacks capacity to make this decision safely, then they must make a decision in Johnny's best interests about how to plan for when he might want to go and look at lorries or show how he could look at lorries in a safer way than standing on the hard shoulder.

Johnny's interest in looking at lorries has a lot more risk attached than whether he should wear his football shirt, and it would be completely wrong to say, 'It's Johnny's choice to go and wander along the motorway so we must let him go'.

But we must not restrict his freedom more than is absolutely necessary. It would be far too restrictive, and not proportionate to the risk of harm, to lock Johnny in the house and deny him access to the outdoors because there is a risk that sometimes he will run after lorries.

Everything you do that might restrict a person's freedom of action must be the least restrictive option that will meet the need – it's not just about letting a vulnerable person do whatever they want, it is about keeping them safe while restricting their rights and freedoms as little as is possible.

## Activity 10

Allow about 5 minutes

What do you think might be the least restrictive option for Johnny, and how could you make the right decision in his best interests?

*Provide your answer...*

### Discussion

The best option, if it's possible, might be to ask Johnny when he's calm what he would like staff to do when he gets anxious. You could also consult his family to find out more about what might trigger this anxiety, and how best to respond.

Perhaps Johnny's care plan could have regular 'look at lorries safely' time built into his walks with carers; he could have a scrapbook of lorries, or collect model ones.

The search for the least restrictive way to meet a need can uncover amazing creativity, and can involve the cared-for person and everyone involved in their care. The delight in finding an imaginative solution that keeps a person safe while respecting their rights is one of the real joys of providing adult social care.

## 4 Emergency care plans

So far in this topic you have learned about positive risk-taking that takes into account the cared-for person's mental capacity, and ways to promote their independence using the least restrictive practice. Now you consider what happens when a carer is unable to continue in their caring role for whatever reason. Depending on the circumstances this might be for an hour or for weeks. In this topic you learn how an emergency care plan can contribute to positive risk-taking and you practise completing such a plan.

### 4.1 Why is an emergency care plan necessary?

Emergency care plans acknowledge the expertise and dedication of carers, and their responsibility in ensuring that as much as possible is done to make sure that the cared-for person continues to receive the care they need. The plans can be made either by the cared-for person or by their carers. However, whoever designs the emergency care plan, it is likely to consist of several similar elements.

Consider for a moment the wide range of activities performed by carers at every minute of every day. Depending on the situation, carers wash the cared-for person, dress them, administer their medication, help them use the toilet and clean themselves, take them shopping and advocate on the cared-for person's behalf. These are just a small sample of roles and responsibilities that carers fulfil. When the carer is not available, the emergency care plan is one way that the cared-for person's needs and preferences can be communicated to others.

It is important at this stage to point out that a situation where an emergency care plan is enacted is not a situation in which the cared-for person is subjected to additional restrictions. It is necessary to ensure that risk is managed in the best interests of the cared-for person, and that any risk management plan is implemented considering the potential positive benefits to that person. So, for example, if the normal carer is not available and less experienced carers take their place, it does not necessarily mean that any activities that the cared-for person normally does for themselves should not continue.

An emergency care plan is not just a document, it is a process. The process should involve preliminary discussions with the cared-for person, their family and carers. The discussions would attempt to foresee any potential emergencies for which the care plan is necessary and plan for them. This might need more than one conversation. At this stage the mental capacity of the cared-for person is discussed and an assessment arranged if it is thought necessary. (Mental capacity is discussed in [Topic 1](#) of this section.)

### 4.2 Drawing up an emergency care plan

Drawing up a good and effective emergency care plan depends on accurate information being known about the cared-for person, and that this information is communicated in a way that others can understand. The next activity helps you to practise communicating information about a cared-for person succinctly and accurately, so that if another carer or professional needs to take action they can rely on the information in the plan to guide what they do.

You can carry out the activity as a carer for a specific person or, if you are not a carer, imagine someone you could be planning for.

### Activity 11

Allow about 10 minutes

Describe briefly the cared-for person's diagnosis and their understanding of it. For example, 'the person has dementia and they do not understand that they are not able to go out of the house unaccompanied'.

- What regular medication does the person take?
- What as required (or PRN) medication does the person take?
- Is there any medication for emergency use and, if so, where is it kept?
- Is there any care the person does not wish? (An example might be not to resuscitate.)

*Provide your answer...*

### Discussion

It's quite difficult being brief when asked to summarise an individual's personality, their needs, preferences and everyday life. However, it should be remembered that this is for an emergency care plan in which small bits of accurate information can be communicated better than larger amounts of information that is not so useful in an emergency situation.

The simplest way to list medication is to copy out instructions provided by the pharmacist or doctor's prescription. This might also be on the box of tablets or bottle of medicine if available. Make sure it is up to date though.

Few people like making life and death choices for a relative but sometimes, such as in end-of-life care, treatments that are available might not be in the best interests of the cared-for person. In other situations, the cared-for person, if they have mental health problems, for example, might prefer not to be taken to hospital in an ambulance.

It is worth thinking about what actions are possible and the potential outcomes and consequences. This might need discussion with professionals as well.

Activity 11 was an initial preparation, which provided essential background information about the cared-for person that can be quickly understood in an emergency. Once an emergency care plan is finalised it should be shared with those likely to be called upon, including relatives, neighbours and professionals. Anyone it is shared with should have been consulted.

Now we would like you to think about what to do if an emergency occurs in the cared-for person's home. Some emergencies are foreseeable and can be prepared for. Examples of foreseeable emergencies include:

- a person with dementia leaving the cooker hob gas on
- a person with dementia getting lost
- a young adult with learning disabilities having an epileptic seizure
- an individual forgetting to take their medication for diabetes.

Other emergencies, of course, are unexpected but plans for them can still be made. In the next activity you will consider foreseeable emergencies for a cared-for person (or an imaginary one if appropriate).

## Activity 12

Allow about 20 minutes

Think of a cared-for person you know. Reflect on where the cared-for person lives and the reasons they are cared for.

1. What are the foreseeable emergencies for which a plan may be needed?
2. Is the cared-for person aware of the potential emergencies?

*Provide your answer...*

Next select *one* potential emergency and:

1. Describe briefly what the potential emergency is.
2. How will it be known the emergency is happening?
3. Should help, such as an ambulance, be called for immediately?
4. What first aid steps can be taken, if necessary?
5. Is there someone close who can be called for additional help?
6. If healthcare professionals arrive, what help should they give, with the most important at the top of the list?

The links below are to an example of a Milton Keynes Carers Trust emergency care plan and the instructions on how to complete it. If you wish, you can use these to help you complete this activity.

- [Emergency template](#)
- [Guidelines on completing the emergency care plan template](#)

*Provide your answer...*

## Discussion

What constitutes an emergency depends heavily on the needs of the cared-for person and the type and level of care delivered. For one person it might be ensuring safety during an epileptic seizure; for another it might be concerned with irregular blood glucose levels. For many people in care potential emergencies can be foreseen. There are often clear indications that certain emergencies are happening, such as fluctuating consciousness. Instructions for situations that require calls for assistance can be described in a brief sentence.

If first aid is required then, of course, the planned helper should be trained in whatever is necessary, and this should be taken into account when consulting on the plan.

## Key points from Section 4

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In this section you have learned:

- what mental capacity is and how it is assessed
- the link between mental capacity and positive risk-taking
- the different ways in which carers can offer support and encouragement to promote independent living and how assistive technology can help some people
- why considering least restrictive practice is important in acknowledging risk while balancing that against empowering and supporting the people you care for to do some things for themselves
- why an emergency care plan might be necessary
- common features of an emergency care plan.

As you are now aware, caring for someone can feel all-consuming, so it is important that carers also take the time to look after themselves. Section 5 offers some suggestions of how carers can look after their own well-being.

## Further information (optional)

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If you are interested in learning more about making decisions on behalf of a cared-for person that are in line with their best interests, the

[Mental Capacity Act 2005 Code of Practice](#) provides a helpful overview – see Chapter 5.



## Section 4 quiz

Well done; you have now reached the end of Section 4 of *Caring for adults*, and it is time to attempt the assessment questions. This is designed to be a fun activity to help consolidate your learning.

There are only five questions, and if you get at least four correct answers you will be able to pass the quiz.

- I would like to try the [Section 4 quiz](#).

If you are studying this course using one of the alternative formats, please note that you will need to go online to take this quiz.

## I've finished this section. What next?

You can now choose to move on to Section 5, Looking after yourself, or to one of the other sections.

If you feel that you've now got what you need from the course and don't wish to attempt the quiz, please visit the [Taking my learning further](#) section. There you can reflect on what you have learned and find suggestions of further learning opportunities.

We would love to know what you thought of the course and how you plan to use what you have learned. Your feedback is anonymous and will help us to improve the courses that we offer.

- Take our [Open University end-of-course survey](#).



# Looking after yourself

## Introduction

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In this section you will be looking at the importance of your well-being and that of the people you care for. People who are in a caring role, either as family carers or who work in health and social care, often find that they are so busy looking after others that they forget to look after themselves. This section offers some suggestions of how to look after yourself.

You will think about different forms of stress and the impact they have on your life and try to find ways of dealing with negative stress.

Making sure you take care of your emotional well-being as well as your physical health is key to a balanced life, so you will also consider ways in which you can support the people you care for to do this as well.

At the end of the section there is a short quiz to test what you have learned about looking after yourself. On successful completion of the quiz you will earn a digital badge.

This section is divided into five topics and each of these should take you around half an hour to study and complete. The topics are as follows:

1. **Why your well-being is important** explains why it is important for you and the people you care for to take care of your well-being.
2. **Coping with stress** looks at different types of stress and the ways you can cope with it.
3. **Work-life balance and professional boundaries** investigates what it means to have a good work-life balance and whether or not this is possible to achieve. It also examines how the boundaries between work and life can become blurred and the reasons for avoiding this.
4. **Person-centred care and self-management** discusses what person-centred care means and how you can support the people you care for to become increasingly independent, as well as the benefits of self-management both to them and to you.
5. **Where to find support** offers some places to go to for support, either in person or online, and the different kinds of support available.

## Learning Outcomes

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By completing this section and the associated quiz, you will understand:

- why looking after your own physical and emotional well-being is vital to your role as a carer as well as for the cared-for person
- the impact of stress and a good work-life balance on your well-being.

# 1 Why your well-being is important

Although most people gain a lot from the relationship with the people they are supporting, the responsibilities can often have a negative impact on their health and general well-being. Carers may dedicate so much time and effort into caring for someone else that they can neglect or do not realise the effect it can have on their own health. In order for a carer to continue caring for as long as they wish to, it is important to be aware of the possible health risks. These can be both physical and emotional.

This is as true for people who are unpaid carers as for people who work in the social care field.

## 1.1 What is well-being?

When people talk about emotional health and well-being, do they mean happiness? Or confidence levels? Or feeling content?

The answer probably includes an element of all those things but a good starting point is to imagine it's a feeling of being able to do all that you want to do.

It is often our emotional or mental well-being that has the biggest effect on feeling well, and the stresses and problems of everyday life, including loneliness and isolation, working long hours and not feeling supported, have a big impact on our mental well-being.

## 1.2 Improving mental well-being

Evidence suggests there are five steps we can all take to improve our mental well-being. If you approach them with an open mind and try them out, you can judge the results for yourself.

### Activity 1

Allow about 15 minutes

#### Part 1

Watch this NHS video about the five steps to mental well-being.

Video content is not available in this format.

## 5 steps to mental wellbeing

Connect

Keep learning

Be active

Give to others

Take notice

The NHS has [further information on their website](#) about what these terms mean:

- **Connect** – connect with the people around you: your family, friends, colleagues and neighbours. Spend time developing these relationships.
- **Be active** – you don't have to go to the gym. Take a walk, go cycling or play a game of football. Find an activity that you enjoy and make it a part of your life.
- **Keep learning** – learning new skills can give you a sense of achievement and a new confidence. So why not sign up for that cooking course, start learning to play a musical instrument, or figure out how to fix your bike?
- **Give to others** – even the smallest act can count, whether it's a smile, a thank you or a kind word. Larger acts, such as volunteering at your local community centre, can improve your mental wellbeing and help you build new social networks.
- **Be mindful** – be more aware of the present moment, including your feelings and thoughts, your body and the world around you. Some people call this awareness 'mindfulness'. It can positively change the way you feel about life and how you approach challenges.

(Source: NHS, 2016)

Can these steps become part of your 5-a-day?

### Part 2

Having watched the video and read about the five steps, now think about whether you already do any of these things or whether you could do more. For each step, try to write down one thing you could do to improve your mental well-being.

*Provide your answer...*

### Discussion

You may have written:

- Get out and about a bit more in my neighbourhood and greet the people that I meet.
- Connect more with family and friends by telephone or email as I don't see them often.
- Learn a new skill or take up a hobby (it doesn't have to be expensive and you can get information about groups or classes at libraries and community centres, or online).
- Volunteer with a charity.
- Think of the good things that have happened each day – this is a step on the way to mindfulness. Being 'mindful' does not happen overnight but with practice and many people find this a useful way to improve their emotional well-being.

We'd now like you to think about the people you support. Their well-being is as important as yours, but how easy is it for them to do any of the things on the five steps list?

### Activity 2

Allow about 5 minutes

Write down in two or three sentences why you think it might be difficult for the person you care for to incorporate the five steps into their life.

*Provide your answer...*

### Discussion

The people you care for may struggle to get in touch with their local community because they find communication difficult or they worry that people will not accept them because of disability or other conditions that they find socially disabling.

They may be inhibited from learning new things because they have told themselves, or been told by other people, that they cannot learn anything new, and they may have got used to a life of inactivity.

Becoming more involved with their community will help the people you care for to see that there are many ways to become 'tuned in' to what is going on around them and to help others in lots of ways, big and small.

## 1.3 Improving physical well-being

Being physically healthy is hugely important. Having a healthy body means you are equipped to deal with the challenges of everyday life, fight off illnesses and function well, allowing you to do the things you want to do. Many physical health conditions are preventable, and being fully aware of potential problems gives you a true choice in whether or not to take on board the information and act to change things.

A balanced diet and regular exercise is a good starting point for looking after your physical health. Caring for others can be exhausting and time-consuming, resulting in constant tiredness, sluggishness and general apathy (that 'can't be bothered' feeling), which can affect work, relationships and many other areas of life. This can also hold back your motivation for getting started on any plans to improve your lifestyle, so taking care of your physical health is an excellent first step to taking care of other areas of your life.

Good physical health is something achievable by everyone, no matter what the starting point. With so much (often conflicting) information in these health-conscious times, we could do with some sensible guidance.

The [carers.uk website](https://www.carers.uk) has a great deal of helpful information about looking after your physical health if you are caring for others. This information applies whether you are caring for loved ones at home or if you are working in the social care services.

Some of the most commonly occurring physical problems for carers are not getting enough sleep, back pain and damage to your back.

If you are not getting enough sleep you may find that you are constantly tired, go to sleep during the day, have trouble concentrating and making decisions, and feeling depressed. Long-term lack of sleep may also increase your risk of high blood pressure, diabetes and obesity.

Lifting and moving the person you care for, and helping them dress can all place a strain on your back. However, knowing how to protect your back can help to keep it in good shape. If you are a paid carer, it is a legal requirement for you to receive training and support in manual handling tasks. Unpaid carers can also access training, so if you regularly have to lift the person you care for, help them to sit or stand, or help them in and out of bed, your local support group or council should be able to tell you about training opportunities in how to lift and move more safely to reduce the risk of harming your back. Alternatively, your district nurse or community support team may be able to show you ways to lift and move more safely. Ask your doctor for more information.

There are many other services that can support you in your caring role and in looking after your own health. These include occupational therapists, physiotherapists, continence advisers and dieticians.

## 2 Coping with stress

Our lives nowadays are so hectic that for many of us stress is so common it has become a way of life. It isn't always bad, though, as a certain amount of stress can help you perform under pressure, motivate you to do your best, and even keep you safe in potentially dangerous situations. It is when stress becomes overwhelming that it can damage your health, mood, relationships and quality of life.

You can protect yourself by understanding how the body's stress response works, recognising the signs and symptoms of stress overload, and taking steps to reduce its harmful effects.

### 2.1 What is stress?

Stress is your body's way of responding to any kind of demand or threat. When you feel threatened, your nervous system responds by releasing stress hormones, which prepare the body for emergency action. Your heart pounds faster, muscles tighten, blood pressure rises, breath quickens and your senses become sharper. These changes help you to deal with the 'danger' your body thinks is coming.

This is known as the 'fight or flight' stress response and is your body's way of protecting you. When working properly, stress helps you stay focused, energetic and alert – for example, giving you extra strength to defend yourself or spurring you to slam on the brakes to avoid an accident.

Stress is also what keeps you on your toes at work, sharpens your concentration or drives you to study for an exam when you'd rather be watching TV.

This is what we think of as positive stress but beyond your comfort zone stress stops being helpful and can start causing major damage to your mind and body.

### 2.2 How do you respond to stress?

All mammals, including people, have three ways of responding to stress:

- Social engagement – making eye contact, listening to others and feeling understood. This can calm you down and help avoid defensive actions such as the 'fight or flight' response. It helps you think more clearly, and things like blood pressure and heart rate continue to work normally.
- Mobilisation (or 'fight or flight' response). This is when we need (or *think* we need) to defend ourselves or run away from danger. Our bodies prepare for action, releasing those hormones we referred to earlier, and our digestive and immune systems stop working. Once the danger has passed, the nervous system calms the body, slowing heart rate, lowering blood pressure and returning to normal.
- Immobilisation – this is the most primitive response to stress, and is used only when the other responses have failed. A bit like a rabbit caught in the headlights of a car, you may find yourself 'frozen' or panic stricken. Some people have even lost consciousness if their life is threatened. This state helps them to survive high levels of physical pain, but until they come



round again their nervous system may not be able to return to its pre-stress state.

(Source: adapted from Leonard Cheshire Disability, 2014)

### Activity 3

Allow about 10 minutes

Think about some situations in your own life and see if you can recall a time when you used each of the stress responses listed above. Write a sentence about each of them.

#### **Social engagement**

*Provide your answer...*

#### **Mobilisation**

*Provide your answer...*

#### **Immobilisation**

*Provide your answer...*

#### **Discussion**

While social engagement is probably the healthiest response to stress, it's not always possible to respond in this way. Many of us have become conditioned to responding to every stressful situation by going straight into 'fight or flight' mode, which over time can raise blood pressure, suppress the immune system, increase the risk of heart attack and stroke, speed up the ageing process and leave you vulnerable to mental and emotional problems.

A 2015 survey by Direct Line Insurance found the top 10 stressful situations for British people were:

1. Not being able to sleep (46 per cent)
2. Losing your keys (37 per cent)
3. Being stuck in traffic when already late (35 per cent)
4. Losing an important paper or document (33 per cent)
5. Nowhere to park (32 per cent)
6. Printer not working when you need to print something (31 per cent)
7. Running out of battery on your phone whilst out (31 per cent)
8. Discovering you are out of toilet roll whilst on the loo (30 per cent)
9. Dealing with machine operated customer service (26 per cent)

## 10. Forgetting your bank card when paying for an item (25 per cent)

(Source: Morgan, 2015)

## Stress overload

Our bodies can't always tell the difference between daily stressors and life-threatening events. If you're stressed over an argument with a friend, a traffic jam on your journey to work, or a mountain of bills, for example, your body can still react as if you're facing a life-or-death situation.

Many health problems are caused or made worse by stress, including:

- pain of any kind
- heart disease
- digestive problems
- sleep problems
- depression
- weight problems
- auto immune diseases
- skin conditions, such as eczema.

## 2.3 How to manage stress

The charity Mind has published a booklet, *How to Manage Stress* (2015). It contains a lot of useful information about living with stress and how to manage it.

Stress isn't a medical diagnosis so there's no specific treatment for it, but if you are finding it hard to cope with things in your life and are experiencing stress, there are treatments available that could help. To access most of these, the first step is usually to talk to your doctor.

Sometimes it may help to speak to a trained professional. Talking therapies, such as counselling and cognitive behavioural therapy (CBT), can help you learn to deal with stress and become more aware of your own thoughts and feelings and why you behave in certain ways. Practising 'mindfulness' (which we talked about earlier) can help you deal with stress by focusing yourself in the present moment and not worrying about things you can't do anything about.

Some people find that spending time outdoors in nature can help to reduce stress. This might include outdoor physical exercise such as running or walking, even tai chi, or gardening and conservation projects, alone or as part of a group.

There is no specific medication for stress because feelings of stress are a reaction to things happening in your life. There are medications that can help to reduce or manage the signs of stress though, and your doctor may prescribe antidepressants, sleeping pills, minor tranquillisers or medication to treat physical symptoms of stress such as high blood pressure. Or you might prefer to try alternative therapies such as acupuncture or aromatherapy. These are not normally available from your GP.

## 3 Work–life balance and professional boundaries

In this topic you will look at the necessity of making time and life away from your caring responsibilities, getting other people involved and the importance of professional boundaries.

You will probably have heard about the importance of work-life balance and how we need to achieve a 'good work-life balance' in order to be happy and successful. There are lots of posts, articles and video chats about it online, and we see it on television and read about it in newspapers and magazines. The problem with all this information is that it can make us feel like we are failing if we don't have everything in check.

But for most of us a perfect work-life balance doesn't exist! The balance part comes from coping with the ever-changing nature of life and work and this is where looking after yourself plays a big part.

For people whose work involves caring for others, either paid or unpaid, your work is an important part of life – it may help to pay the bills and gives a sense of purpose. Caring for others can be extremely rewarding. It can also be tiring, demanding and painful.

Work, though, is just a part of our lives. For some carers it feeds into every aspect of life, which is why finding a way to balance this part of life with everything else that's important to us will make us feel more in control and therefore improve our well-being.

### 3.1 What is a work–life balance?

The answer to this question varies for everyone but basically it's the amount of time and focus you give your work versus other aspects of life. This is why at the beginning of this topic we said that a perfect work-life balance doesn't exist!

Of course, many unpaid carers have to fit in paid work around their caring responsibilities, which makes achieving the perfect work-life balance even more of an impossible dream. Naturally, everyone's priorities change depending on their circumstances and so the balance changes as well.

#### Activity 4

Allow about 20 minutes

Read and reflect on the case study below before answering the questions that follow.

#### Case study: Edward's dilemma

Edward is a marketing manager for a children's charity. He is not married and lives with his partner, Mark, who works as a self-employed IT consultant. Mark has been experiencing memory loss and mood swings for some time, which the couple thought was caused by stress, but he recently received the news that he had developed early onset dementia and that his condition would deteriorate rapidly. The couple know this will have a huge impact on the way they live their lives and

want to be prepared for how they will manage, particularly the end-of-life care that Mark will need.

Edward loves his job and receives a lot of satisfaction from it. But he also wants to be able to care for Mark as his condition worsens and he needs regular care and support. They know things will be difficult for both of them but want to make the most of the time that remains to them in a positive way.

What steps can Edward and Mark take to adapt to the changes in their work-life balance and make sure they are still leading positive and fulfilling lives?

Write a sentence each about:

1. What support do you think Edward might need from his employer?
2. What practical support might Edward and Mark be able to obtain?
3. What can Edward do to retain his feelings of self-worth and value if he becomes a full-time carer?
4. What can Edward and Mark do to make the end of Edward's caring role and his return to work as positive as possible?

*Provide your answer...*

## Discussion

### 1. Taking time out from work and flexible working

Becoming a carer no longer means an 'either or' decision between working and caring. In many situations it is possible to do both if you want to.

These are some of Edward's options for time off from work, or changing how he works to enable him to continue working as well as caring:

- emergency time off for a dependant
- flexible working
- compassionate leave
- unpaid leave
- career break/extended unpaid leave.

### 2. Practical help with caring

Practical help is essential for Edward to be able to look after his own well-being and to find the energy to continue caring. Practical help includes having a carer's assessment, which will look at Edward's role as a carer and what he needs to be effective, including how caring impacts his work. This is obtainable from local social services departments.

Mark may be eligible for community care if he needs help with day-to-day living such as mobility, cooking, washing or getting dressed.

Family and friends will want to help Edward and Mark but may not know what to do. They should ask for help with specific practical things, such as shopping or cooking, and this will help people know what support to offer.

Mark and Edward could contact organisations such as the local carers' centre, or Carers UK. They could contact dementia charities or their local church, mosque or synagogue if they have a religious faith.

### 3. Edward's well-being

Edward will need to take care of his own well-being if he is to become Mark's full-time carer eventually. Taking regular breaks will help him to keep his emotional balance and remain strong. Of course, being a full-time carer doesn't always mean you cannot work, and once his caring duties settle down Edward may decide to think about how he can balance his career with his caring role. Edward's career is important to him and gives him a sense of connectedness, intellectual satisfaction and a feeling of being able to influence and being valued. Understanding these needs will help him design a positive work-life fit for himself and Mark.

### 4. Life and end-of-life planning

Edward's caring role will eventually end, as Mark's condition will either worsen to the extent where he can no longer be cared for at home or his life will end. While Mark still has capacity he will be able to make plans and decisions about his wishes for the future and his future care. He and Edward will need to be flexible enough to make the most of the good times, especially as they get less frequent. When this stage is reached, Edward will need to cope with this drastic change, and manage his return to work. Depending on the circumstances, Edward will be able to phase his return to work over a period of time that again takes into account his needs and enables him to re-establish his work-life balance.

## 3.2 Unpaid carers

According to the [Carers Trust](#), a charity that works to improve services and support for unpaid carers, there are approximately 7 million carers in the UK, and 1.4 million of them provide more than 50 hours of unpaid care per week. In a survey carried out by the charity, almost half these people sought help only after they were made aware it was available for them.

Anne Roberts (2012), Chief Executive of the UK Carers Trust, said: 'As this survey shows many unpaid carers have never accessed any support services to help them in their caring role. We already know that many carers simply don't have any awareness of the kind of help that is out there and what a huge difference it could make to their lives.'

Trying to carry out caring responsibilities without support can lead to serious problems that can affect carers' working lives and their mental and physical health. Norman's story is an example of what can happen.

## Case study: Norman

Norman had to stop working in 2008 aged 56 to become a full-time carer for his wife, Linda, who has multiple sclerosis. He explains: 'I was struggling with keeping my job going and trying to ensure that my wife was safe enough to allow me to go out to work. The pressure on me eventually led to my own health failing. The stress of trying to manage a challenging job and cope with Linda's needs led to me ending up in the cardiac unit at our local hospital.

'I was left with no choice but to give up my job and become a full-time carer. The impact of this choice had serious financial implications and this led to depression and a feeling that I had gone from being a person to a resource called "carer". I was invisible.

'When I first contacted my local carers' centre, I spoke to a Carer Support Worker and for the first time in many years, there was someone willing to listen to me rather than offering the usual retort of "but it is much worse for your wife because of her illness". The carers' centre helped me to restore my self-respect and confidence and now I feel proud of what I do to look after Linda.'

(Source: Carers Trust, 2012)

In this topic you have learned that the idea of being able to perfectly balance work and the rest of your life is not realistic, and this can cause people more stress by trying to live up to unrealistic expectations.

What is possible, though, is to seek a better balance in your life, with work and the rest of your life. This will help give you a quality of life that you can manage without making yourself physically or mentally ill. It is not possible to achieve this without help though, and we know now that employees have rights that will support them to achieve this balance. Unpaid carers also have support, although many of them are less aware of the kind of help they can expect.

## 4 Person-centred care and self-management

Working in a person-centred way and encouraging people to manage aspects of their own care is good for you and for the person or people you are caring for. A person-centred approach to care will focus on the individual's personal needs and goals, which brings them to the centre of the support they are receiving.

This topic looks at encouraging the people you support to take some responsibility for their own care and management. This is important for their well-being and also gives you some time to enjoy the person you are supporting. Supporting the cared-for person in the way that works best for them leads to better emotional and physical well-being for both parties.

### Activity 5

Allow about 10 minutes

Listen to this audio podcast about meeting the needs of Jackie, who has a visual impairment.

Audio content is not available in this format.

[Living with visual impairment](#)

Jackie talks about how she needed not only support but also empowerment from her carers. Try to put yourself in the role of Jackie's carer, and think about how you would support someone with a visual impairment without making them feel they are losing their independence.

- How do you think Jackie feels?
- What could be done to improve Jackie's quality of life?

This audio is provided for use within the course only.

*Provide your answer...*

### Discussion

Jackie was worried about not having a diagnosis for her condition, and felt that the healthcare team would not notice her symptoms. Her carer would need to remain supportive and attentive, asking her to speak about how she was feeling and what support she needed.

Jackie talks about the balance between allowing a person the independence to carry out everyday tasks, and supporting them to do so. Jackie's independence is important to her so you would need to think of ways to make her feel independent, such as helping her to find out about aids to enable her to carry out tasks on her own, but still being on hand to offer support should she need it.

Jackie may benefit from assistive technology to improve her quality of life, such as a large keyboard or talking telephone, books in large print or Braille. Assistive

technology is covered in Section 4 of this course; see Topic 2, '[Promoting independence](#)'.

## 4.1 Providing the right kind of support

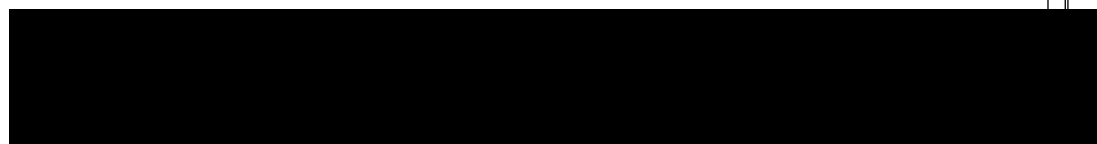
People receiving care should have a care plan that has been written by them (if they have capacity), with support from their carers. The care plan will help others to know what care should be provided, but also how to support that person in a way that is right for them.

### Activity 6

Allow about 10 minutes

Video content is not available in this format.

Working in an empowering way – it's too early



### Scenario One

"It's too early"



Watch this video and think about whether Tim was receiving person-centred support.

- Do you think Tim's carer had looked at his care plan to see what kind of start to his day Tim would prefer?
- How could she have managed it differently?



- How do you think Tim felt?
- What could Tim have done differently?

Make some notes in the box below.

*Provide your answer...*

### Discussion

Tim's carer was not working in a person-centred way. She did not consider his privacy when she entered the room without knocking or checking to see whether he was ready to get up.

When Tim asked for 'another five minutes' she could have gone to see if the next person was ready to get up and come back to Tim afterwards.

She could also have asked Tim what he wanted to do about his breakfast – perhaps he could have had it in his room if he wanted to stay in bed.

Also, she didn't need to get his clothes out for him. Tim could have told her what he wanted to wear when he was ready to get dressed.

The carer's actions shown in the video would have made Tim feel helpless about everyday decisions about his own life being taken out of his control. There wasn't much Tim could have done at that moment because the carer was not listening to him – she was just focusing on getting through her tasks of getting people up and ready for breakfast. But Tim could have arranged to have a 'please knock' sign put on his door for a start, and he could also have put into his care plan that he liked a lie-in in the mornings so that he could be left longer before care staff got him out of bed.

Having some control over our own lives is vital for our well-being.

## 4.2 A different approach to support

Nottinghamshire County Council has developed a scheme called a strengths-based approach. The strengths-based approach is also referred to as an 'assets-based approach' in Scotland and has been promoted by the Institute for Research and Innovation in Social Services (IRISS) for a number of years. For example, see the IRISS publication [Using an assets approach for positive mental health and well-being](#).

This type of approach helps to encourage people to become more independent by gradually withdrawing support once the carer can see the person has the skill or strength required to carry out certain tasks independently. This has the benefits of support still being in place as long as the person needs it, while allowing the cared-for person to become increasingly independent and self-sufficient.

In the next activity you will watch a video about Julie, who has mental health problems. Cheryl, from United Response in Nottinghamshire, supported Julie in her efforts to achieve a high level of independence. Julie wanted this independence so that her daughter Leanne, who had been caring for her, could move away from home.

## Activity 7

Allow about 20 minutes

Video content is not available in this format.

Care Act – Promoting independence



As you watch the video, think about what Cheryl did to enable Julie to take the steps towards independence. Make a note of your thoughts.

*Provide your answer...*

### Discussion

The first thing that Cheryl did was to establish a relationship with Julie by finding out what was important to her and what she could already do. Cheryl then built on these foundations to give Julie the confidence that she could manage certain activities independently. These initial steps helped Julie to gain the self-confidence and self-esteem to take further and more difficult steps.

Both women acknowledged that there was a long road ahead but that it couldn't be rushed. As Cheryl worked with Julie, she would be able to gradually withdraw the level of support and Julie would do more and more for herself.

It was evident from the video how much this has increased Julie's well-being and that of her daughter, who was also working towards her aim of being able to leave home.

## 5 Where to find support

There are many online support services giving information and guidance on different ways to manage stress, such as [Mind](#). Mind also provides a translation service – language line – for support in languages other than English.

Online communities such as [Big White Wall](#) and [Elefriends](#) are helpful and provide support for people who are finding it hard to cope. These online communities are completely anonymous, which allows people to speak openly in confidence.

This website is useful for online services in Wales:

<http://www.mentalhealthwales.net/voluntary-sector/>

Local authorities now have 'living well' and well-being services – online and in the form of leaflets and related information, support groups, workshops and courses. You can find more information online, for example on the NHS [Wellbeing website](#), or through your doctor, local library, Citizens Advice Bureau or local council offices. These places will also be able to provide you with information about other local community groups and support if you prefer an offline approach.

[Time to Change](#) is an organisation that challenges mental health stigma and discrimination. It also provides information on stress and workplace well-being for employers and employees.

You heard from Norman about the support he received from the [Carers Trust](#). There are other organisations like this, such as [Care UK](#), who also offer support and guidance.

### Activity 8

Allow about 15 minutes

Search online for five well-being support groups.

List them here and write a short statement about what they do.


If you would rather not go online where else can you seek support?

Write down three places you could go to for support.

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### Discussion

It is relatively easy to search online for all kinds of support – both for general well-being and for support for specific conditions. It is not so easy to begin to seek out support without the aid of the internet but your doctor would be a good place to start, as would a Citizens Advice Bureau, local council office or public library.



## Key points from Section 5

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In this section you have learned:

- why it is important to look after your own well-being and that of the people you care for
- some strategies for coping with stress and to understand that not all stress is bad for you
- that a healthy work-life balance and establishing boundaries is important for your physical and emotional well-being
- more about person-centred care and self-management
- where you can find support.

The 'Next Steps' section provides you with the opportunity to reflect on what you have learned on this course and to consider what you would like to do next. It will also give you information about options available to you for further learning.

## Further information (optional)

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[Stress symptoms, signs and causes](#): this article from HelpGuide contains information on the signs and symptoms of stress and some suggestions on how to cope with stress and stressful situations.

If you are employed as a carer, you have certain rights to help you achieve a good work-life balance, such as flexible working, time off work for emergencies involving dependants, shared parental leave and paid annual leave. The [Working Families](#) website has lots of information to help working families achieve a healthy work-life balance.

[A Pocket Guide for Employees: Balancing Work and Being a Carer](#): this is a guide written by Liz Morris with Susanne Jacobs for Working Families (2012). The guide offers practical help and support to enable carers to balance paid work with their caring responsibilities.

## Section 5 quiz

Well done; you have now reached the end of Section 5 of *Caring for adults*, and it is time to attempt the assessment questions. This is designed to be a fun activity to help consolidate your learning.

There are only five questions, and if you get at least four correct answers you will be able to pass the quiz.

- I would like to try the [Section 5 quiz](#).

If you are studying this course using one of the alternative formats, please note that you will need to go online to take this quiz.

## I've finished this section. What next?

You can now choose to move on to Taking my learning further where you can reflect on what you have learned and find suggestions of further learning opportunities.

We would love to know what you thought of the course and how you plan to use what you have learned. Your feedback is anonymous and will help us to improve the courses that we offer.

- Take our [Open University end-of-course survey](#).





# Taking my learning further

## Taking my learning further

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By studying this course you should now be able to:

- describe the role and responsibilities of carers
- recognise some of the basic concepts that will enable a person-centred approach to care
- identify the different needs of a cared-for person at different stages of their care
- understand the impact that caring may have upon carers, and how responses might be managed
- explain some of the legal responsibilities within the caring role.

# Health and Social Care degree qualifications

If you would like to take a more in-depth look at studying health and social care then you can find out more at The Open University's [Health and Social Care qualifications](#) website.

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## Text

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Activity 9: Text: Teacher Support Network and Robert Latham, 2016

<http://www.bewellteachwell.org.uk/relationships/listening>

### Palliative and end-of-life care

Activity 2: Extract from World Health Organization (WHO) (2015) *Cancer* [online].

Available at <http://www.who.int>

Activity 4: Text from <http://www.skillsforcare.org.uk> Skills for Health & Skills for Care (2014) *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life* (2nd edn), Leeds and Bristol, Skills for Health & Skills for Care.

Activity 5: Part 1: extract from Department of Health (2011) *Finding the Words*, Leicester, NHS National End of Life Care Programme.

## Looking after yourself

Section 2.2: Text extract from Morgan, M. (2015) 'Sleepless nights, being stuck in traffic and running out of loo roll WHILE on the toilet: The top 10 everyday things that Brits find most stressful revealed', *Daily Mail*, 10 April 2015.

Section 3.2: Extract from Carers Trust (2012) *New Charity Finds Many Unpaid Carers Battle for Years without Help* [online]. Available at <https://www.carers.org/press-release/new-charity-finds-many-unpaid-carers-battle-years-without-help>

## Videos

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Activity 3: Transcript: (Stephen Fry) from Keeping Britain Alive, Episode 2 © BBC

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