



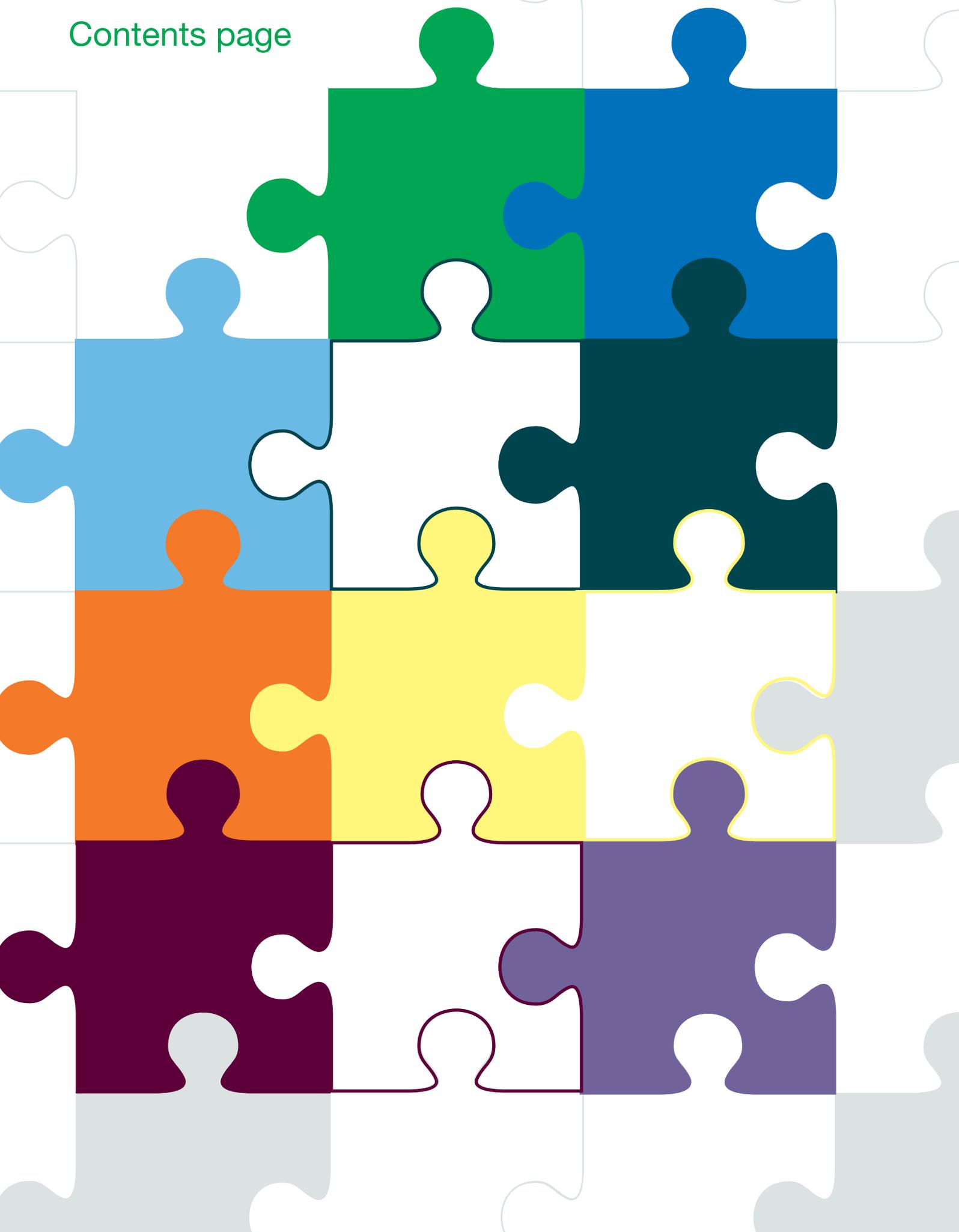
Understanding roles: working together to improve end of life care

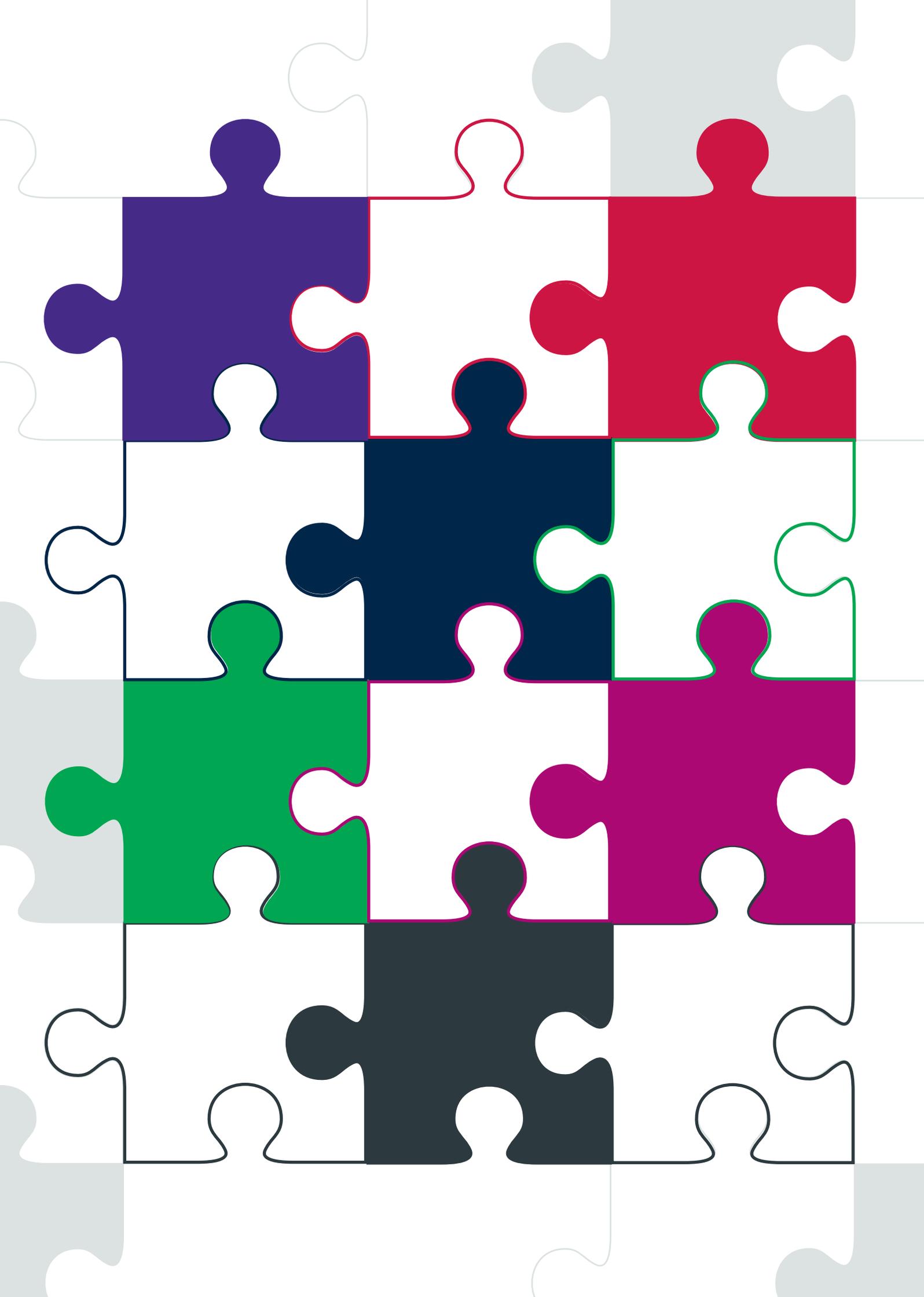


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Introduction

It is only by understanding the roles, skills and experiences of others that it is possible to work together effectively to give people who are dying the very best care and support at the end of their lives.

This booklet complements the film '[Understanding roles - working together to improve end of life care](#)' by briefly describing a range of people and roles that may be involved in end of life care and how they work together. It draws on the experiences of people who use care and support services, those with personal experience of caring for someone close to them at the end of life and professionals who provide care. You can watch the film online by visiting www.skillsforcare.org.uk/endoflifecare.

Information shared in the film and this booklet comes from conversations with people who currently carry out the roles described. The exact nature of roles varies both individually and regionally. This isn't, therefore, a definitive guide but illustrates the kinds of activities that are common and core in end of life care.

In the film and this guide, the person receiving support from health and care services has Motor Neurone Disease but the information they share could be relevant to any condition. Similarly, the issues identified by the primary carer are some of those commonly identified by carers supporting someone who is dying.

Whilst each individual role is important, it's crucial that everyone comes together to support the person who is dying and those close to them. In order to do this, usually a member of the team takes on the role of co-ordinator or 'key worker', taking responsibility for ensuring that all involved are working together and have the information that they need, including carers and family members. This activity can be undertaken by any member of the team, giving flexibility in how they respond to people's individual strengths, needs and circumstances.

It is important to remember the crucial role that volunteers, voluntary and charitable organisations play. This can range from individual friends or neighbours giving their time to larger organisations who fund professional roles, such as specialist cancer or dementia nurses, or organisations who provide care and support directly, such as carer support organisations.

Many people describe their role as 'looking after the whole person'. This involves understanding and responding to what is important to the person who is dying and those close to them, for example, their culture, faith, spirituality, relationships, interests, priorities, work, finances and physical and emotional concerns, such as pain or anxiety. The term 'holistic care' is sometimes used to describe this.

When we talk about 'carers' we're referring to people who provide unpaid, informal support for people who are close to them, such as family members or friends. Sometimes the person providing the majority of that care is called the primary carer.

The key messages for all professionals working to support people at the end of life are:

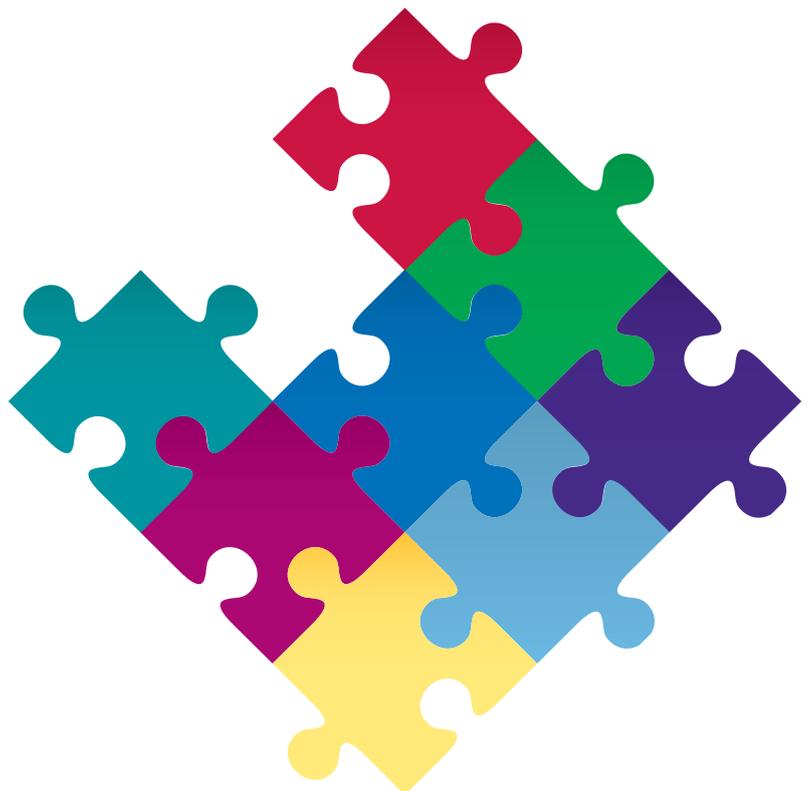
- always keep the person who is dying and those close to them at the heart of your decisions
- it is impossible to know everything; don't be afraid to ask others for help
- find out who can help and how to contact them (you can record this information by adapting the form on page 28)
- it is important to share information appropriately with members of your team and family/carers
- end of life care can be hard, everyone in the team needs to support each other.

“ All of me needs all of you to work together ”

Sanjay, a person with advanced Multiple Sclerosis

“ Once everyone started working together, the care we had was brilliant. I couldn't fault it and will be eternally grateful for the care and support we received ”

Former carer



The person who is dying

There are many people involved in and who continue to be part of my care. My wife and GP have been my primary care givers, but as my health worsens I'm seeing more people, including specialists for my condition, physiotherapists, specialist nurses, palliative care consultants, hospice staff, a range of therapists, social workers and a care agency.

Then there is my pharmacist who provides vital support, and as I have a range of health issues, I have additional appointments to go to every few months.

I have Motor Neurone Disease (MND), so organisations such as the MND Association and my local hospice have also been integral to improving my quality of life and independence.

When I was first diagnosed I had to learn a whole new language relevant to my care, and didn't know how to access support. It was a challenge to know who to ring, and often the people I contacted didn't know how to help or where to send me. Sometimes they didn't ring back and I would feel helpless.

Eventually I made contact with a social worker who understood the various systems and could explain the different roles and right people to contact. He listened to what I needed, focused on what could be achieved and made sure I was kept up to date with available information.

Having the support I need allows me to worry less about my health and make the most of every day, which is very important to me. It's hard enough living with a condition, but try to imagine how hard it is when the services don't communicate and fail. It's important to remember that I'm a person, not a disease.

What I need from others

- people who call back
- translation of medical and health language into plain English
- help with understanding and pulling all the systems together
- people to listen to me and remember that I know what I need and what helps
- compassion
- respect for my capacity to make decisions regarding my care
- my care information to be shared appropriately with everyone who needs it.



Primary carer

I looked after my sister when she was ill and dying. When she was first diagnosed our whole world was turned upside down. We were dealing with so much emotionally and there was so much information we had to find. It was hard to know where to start. I looked things up on the internet and contacted many organisations trying to learn as much as I could. At times it was incredibly stressful and depressing and I felt quite overwhelmed.

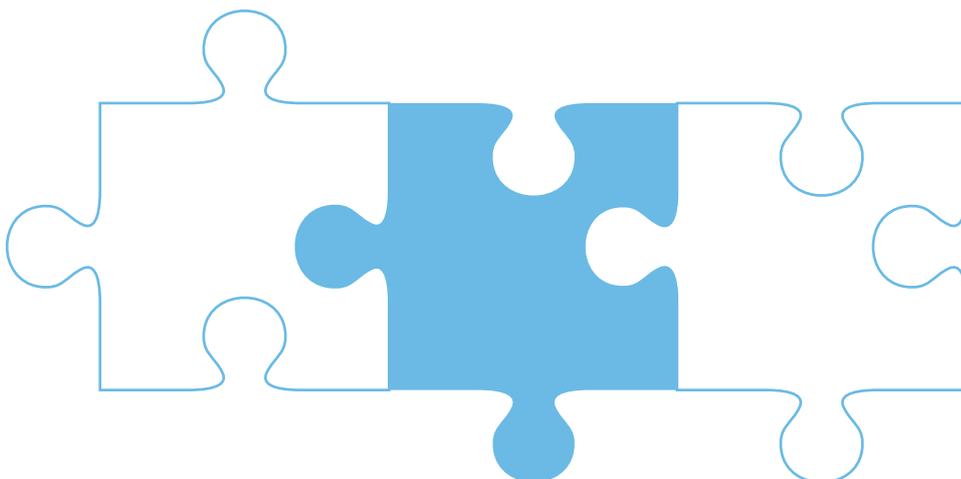
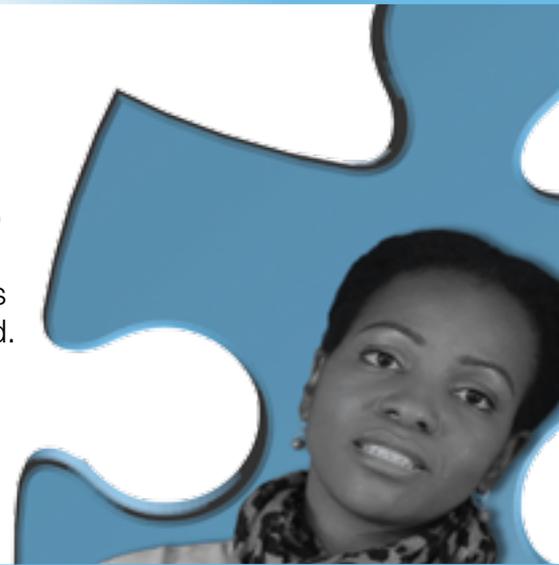
The care my sister needed was outside of my experience but I wanted to do the best for her and her son. It was a huge learning process for all of us. I felt that it was my job to make sure all the practical things were taken care of so that she could maintain her quality of life.

There were so many things to sort out – getting benefits because she couldn't work, trying to fit everything in around my work, organising the various support services who could really help us, getting a blue badge because she couldn't walk far and learning about things like stair lifts and hoists. With the help of a social worker we finally started making sense of it all. And one of the key things I had to learn was that one of my responsibilities was to look after myself.

With the right guidance I developed the tools I needed to be her primary carer and to help my nephew through such a hard process. The support we received made it possible to enjoy the time we still had as a family.

What I needed from others

- people who returned my calls and responded to our needs
- support that empowered us and respected our boundaries
- help with translating medical and health language into plain English
- help with understanding and pulling all the systems together
- support that let me also look after me
- compassion
- respect for my role as my sister's primary carer and in the decision-making process.



Commissioner

What I do

Commissioners have responsibility for planning, agreeing and monitoring the care that is provided to the local population, within the funding available for services in their area.

How I contribute

I contribute to end of life care by making sure that we have teams of people in place to deliver the care.

My work is very varied. To make sure the right care is in place we have to understand who lives in our community and the needs they might have. For example, we might know that a percentage of the local population are elderly, which means that there may be a bigger need for end of life care than in other areas. We might have a large population of people who have dementia, so will need to make sure that the right teams of staff and organisations are in place to support them.

Making decisions about who provides the care within our community can involve looking through 'bids', which are like application forms, from organisations who can provide care to find out about their experience and make sure that they can deliver high quality care within the funding that we have available. The organisations that provide care can be voluntary organisations like Admiral nurses from Dementia UK or Marie Curie and Macmillan nurses.

We set up contracts with organisations who provide care to make it clear what we expect from them and what they can expect from us. For example, we might say that they must show evidence of really listening to members of the community to ensure that they're learning from their experiences and always improving the care provided.

To help us make decisions about the care that is needed and how to provide it, we meet regularly with doctors, nurses, people who use services and members of the whole team.

I try to ensure that everyone in the team is working together and sharing information so that people at the end of life see us as one service, not lots of individual people doing different things.

We support the organisations providing care by designing training programmes, writing a regular newsletter which contains information about, for example, national guidance for end of life care or courses and conferences that might be helpful.

What I need from others

- up to date, accessible information about the latest guidelines, strategies and policies, including what this needs to mean in practice
- a good working network willing to communicate across all organisations
- for people to put the person at the centre and think about what we can bring to the person's end of life care
- sharing information so that families don't have to keep repeating the same information people to be open in seeing how they can improve the care they give.



Dietician

What I do

Dieticians work in the community, hospitals and hospices to promote the well-being of individuals and communities to prevent nutrition related problems.

How I contribute

I work in a hospital, hospice and the community to support anyone with conditions that can deteriorate and people who are nearing the end of their life and their families. I try to ensure that they receive the nutrition and hydration they need to feel as well as possible and have energy to enjoy life.

I basically listen to patients and families to understand their concerns and try to help them. The kind of help I offer is very dependent on how long people have to live. For example, some people might live for years with a long term condition or life-limiting illness. They may therefore want and need to be more active than, say, someone who is very near the end of their life. In these situations we can advise people on the kinds of healthy and nutritious foods that can give them the energy needed to continue living an active life.

If someone is receiving medical treatment like surgery, radiotherapy or chemotherapy, they may feel exhausted, their appetite may change and so might their sense of taste. They may need a particular kind of diet, such as soft foods only. Some conditions affect the body's ability to absorb the nutrients and calories needed from the food and drink that is consumed and medication can make people feel nauseous. We can advise people on what kinds of things to eat and when, so that they build up a reserve of energy to help them through their treatment and sustain them during the more difficult periods of their illness.

When people are very much closer to the end of life, they may not wish to eat or drink. Some people may find it difficult to swallow. We can suggest eating smaller amounts more frequently or serving food on smaller plates to make it more appealing, or alternative ways of gaining nutrition and hydration.

Regardless of their health or condition, people have their own preferences and needs, such as likes and dislike, allergies and eating and drinking habits. Food is also extremely social; changes to food and appetite can affect people's desire to take part in social activities. Spirituality and religious beliefs can also play a part in how and when people eat and drink. I can help people to plan ahead by giving ideas about the kinds of things that they may be able to eat that are still tasty and nicely presented, in line with their spiritual and religious beliefs and practices.

In hospices, I observe how people respond to food. If, for example, they say that the food is wonderful but don't eat it, I chat with them to find out whether there is anything they would prefer or find easier to eat.

Family members and carers can be very concerned if the person they're caring for is losing weight or doesn't seem to want to eat. We can reassure them and offer practical suggestions about the kinds of things to offer.

What I need from others

- for people to understand that food is important and to try not to forget about this important aspect of life and care's all organisations

District nurse

What I do

District nurses are sometimes referred to as community nurses and play an important role in providing care for people in their home or care home.

How I contribute

I lead a team of nurses and healthcare assistants to provide care in the community. I often work with people and their families over a period of time, so get to know them quite well. As a result, I can notice when their health is deteriorating and they are nearing the end of their life. I also have a good understanding of the local community and am able to access help from a wide range of resources.

In these situations I spend time with the person who is dying and those close to them, helping them to understand the situation and what may happen in the following days or weeks. For example, carers often ask how they would know if the person was dying or what they should do if the person dies in the middle of the night. Patients might want to know what will happen to them when they are dying.

We are often the key worker in end of life care situations and work very closely with other people to provide the care that is needed for the person and family.

Carers and family members can find the responsibility quite overwhelming at times. We can offer reassurance, support, a listening ear, practical support and guidance.

We help families to discuss the kinds of things that might be important to them at this point in their life. For example, I find out if they have strong feelings about where they would ideally like to die. Because I know what's available locally, I can help people to make informed choices.

On the medical side, we have the skills, knowledge and experience to provide nursing care just like hospital nurses but with the additional qualification to work in the community. As well as providing emotional support, we do things like giving medication, monitoring pressure relief and catheterisation. The important aspect of end of life care is to ensure people's symptoms are controlled and we monitor the person closely making changes as necessary. We sometimes visit more than once a day and often arrange 24-hour telephone support. When people need support with other things like getting out of bed and getting washed or dressed, we work with social services to arrange for care, support and equipment to be put in place.



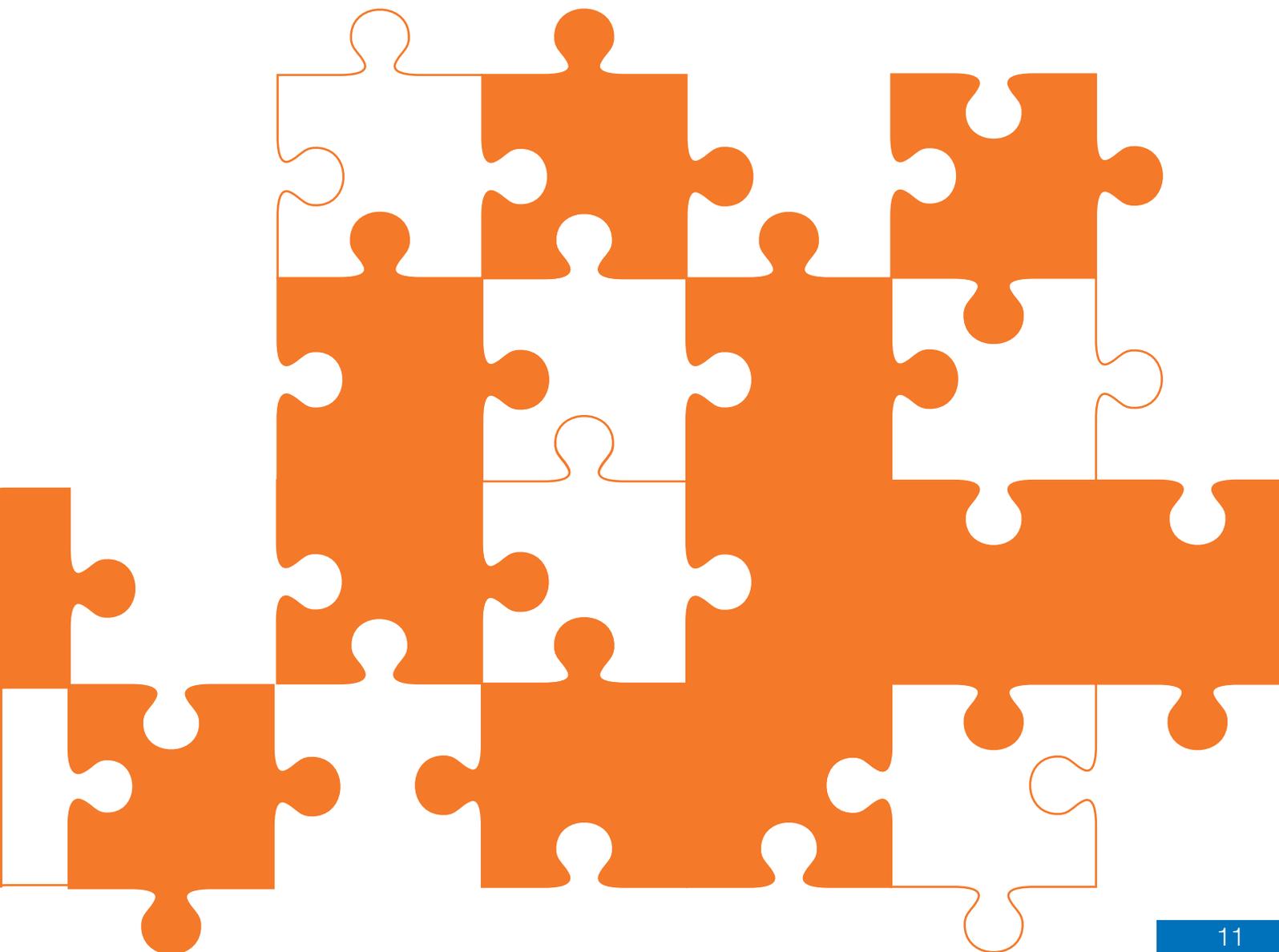


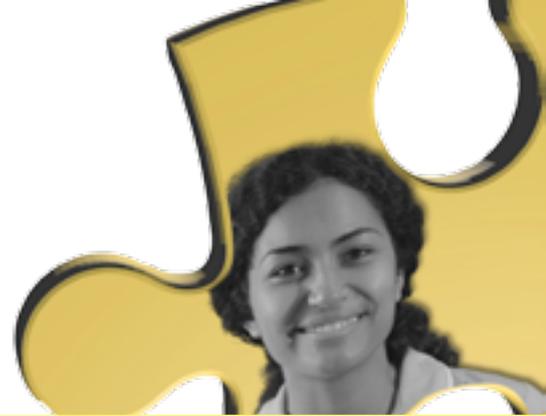
We work closely with the GP and other professionals and organisations involved, often acting as an advocate for the patient and their family. We try hard to avoid unnecessary hospital admissions, especially when the person would like to die at home.

I often find that spirituality and faith are especially important to people at this time in their lives. I'm always happy to listen and can sometimes help by putting people in touch with, for example, chaplains or spiritual leaders.

What I need from others

- to know who else is involved in the care and talk to them regularly
- to assess people's needs early so that I can plan ahead and avoid crises
- a supportive attitude from everyone involved
- people taking responsibility for their aspect of care
- to know that other services will support the patient when I am not around
- everyone knowing the patient's wishes.





Domiciliary (home) care worker

What I do

Domiciliary care workers care for and support people who still live in their own homes but who need additional support to remain independent and have quality of life.

How I contribute

My work isn't only about end of life care but I come into contact with it quite often because many of the people we help are elderly or confined to their homes because of their health.

I help with day-to-day things like making people cups of tea, helping them to eat, wash, get dressed, and move from the bed into a chair, sometimes using a hoist.

I don't always have much time with people but because we're in their home, we often get to know them quite well. Sometimes I'm the only person they see all day.

If family or friends are involved, we chat to them and can learn a lot about what's important to the person who is ill, what they like or don't like or how to communicate with them. This is particularly important if the person has dementia and may become agitated or upset by having someone they don't know looking after them.

By being there, we can support the family and carers, giving them a break and time to do other things. They're often caring 24/7 so even just a short break while we're there can be a help. Sometimes I help with things like cooking, shopping or cleaning too.

I'm not trained in health care but often work with district nurses and GPs, for example, sharing information about any health issues that concern me. Because we see people quite often, sometimes daily, we notice if they are looking unwell and can see when they are deteriorating and may be nearing the end of their life.

The person we're caring for and their family often start talking to us about all kinds of things, for example, worries they may have about how they will cope when the person dies. People seem to value having someone to talk to. We notice when people have particular religious or spiritual images, icons or books and try to make sure that we are respectful and help the person to observe any rituals that are important to them.

Sometimes we are with the person when they die or arrive to find that they have died in the night. This can be really sad. We work with GPs and district nurses to make sure that the person and their family are well cared for until the end of their life. We sometimes attend the person's funeral too.

What I need from others

- to understand what the person and their family want and need
- I need to be listened to by others who provide care when I tell them about the client because I get to know them well
- I need support and to know who to go to if I'm not sure how to do something. information people to be open in seeing how they can improve the care they give.

Funeral director

What I do

Funeral directors are responsible for making sure that the person who has died is cared for with dignity and supporting the family with all aspects of organising a funeral.

How I contribute

I support families and friends through the whole process of organising a funeral. This can start with a telephone call from someone who wants to discuss their own funeral arrangements or a family member whose relative is dying, as well as after someone has died.

Our team provides as much or as little support as the family would like. For example, we may simply offer information and the family will organise the whole thing, or we may meet with the family several times and be involved in all aspects.

When and if the family want us to, we collect the body. We send two members of the team to do this and encourage the family to take their time and to help if they would like to. We also provide opportunities for them to spend time with the person who has died.

Before the funeral we often meet with the family to explain the relevant paperwork that is needed and support them in completing it, especially if the person is being cremated. We then discuss the kinds of things that are important to them such as what kind of ceremony they would like and choosing a coffin.

We can help to arrange all practicalities such as flowers, orders of service and music. We liaise with the crematorium or burial ground to book the ceremony and explain the family's requirements.

We can also work with spiritual, religious or non-religious leaders such as priests, vicars, rabbis and celebrants to make sure that everyone is in agreement about what will happen and clear about what needs to be done.

We can travel with the family to the ceremony, who we encourage to participate on the day, for example, by carrying the coffin. If it's a cremation, we can collect the ashes from the crematorium and deliver them home to the family.

Our main roles are to listen, to explain the options that are available and to empower people to make choices that matter to them.

What I need from others

- open-mindedness, compassion, flexibility, kindness, respect and a positive approach
- an understanding that every family is unique, and that we have a responsibility to listen to their needs and to go out of our way to meet those needs
- to think 'how can we achieve this' rather than 'we don't normally do that'
- to remember that the person who has died is and was precious to someone and to treat them accordingly.

GP (General Practitioner)

What I do

A GP is a doctor who works in the community rather than in hospital. They provide a range of health services including advice on health problems, vaccinations, prescriptions and referrals to specialist help and support.

How I contribute

I work as part of a team with healthcare assistants, practice managers, receptionists, district nurses, social workers and others to support patients and families who are being cared for in the community, such as at home or in a care home. I see patients and carers of all ages with anything from minor health issues to life-limiting conditions.

Because we see our patients and their families over a period of time, we get to know them quite well. We're often involved in all aspects of their health care, however minor and provide emotional support too. In situations where people are dying or nearing the end of their life, we've often been involved from the very start, with patients or their families having come to us because they were concerned about issues that they had been experiencing. We have often referred them to a specialist doctor or nurse at a hospital. We tend to be involved in certifying that someone has died and support the family after the person has died.

We are able to identify when someone is deteriorating or close to the end of their life, and have conversations with the patient and family to explain the situation, what to expect and the support that can be provided.

We can help to keep people comfortable, for example, by prescribing pain relief medication or oxygen to help if people are breathless. Along with district nurses and healthcare assistants, I support families, especially if they are concerned about any aspect of care or the medications that are needed. To avoid delays, especially during evenings and weekends (also described as 'out of hours'), we often arrange what we call 'just in case' boxes which contain medications that might be needed in future. This is sometimes called 'anticipatory prescribing'.

I visit people at home and make sure that services who provide care during the evenings and at weekends know people's end of life care wishes, particularly for resuscitation. I make sure families know what to do if someone deteriorates so that they're not rushed to hospital unnecessarily.

I try to explore and understand what's important to people including, for example, if they have particular spiritual beliefs and how I might be able to respond and offer support.

What I need from others

- good communication with families and district nurses about how the person is responding to medication
- everyone involved to know their wishes and what to do if they deteriorate or die
- electronic palliative care co-ordination systems for sharing information
- clarity about the level of support that is being provided, also known as a 'care package'.





Grief/Bereavement counsellor

What I do

Bereavement counsellors can support and help people to come to terms with their loss and grief and adjust to a new life with all its changes.

How I contribute

We can help people to manage the difficult emotional, practical and spiritual aspects of dying and bereavement.

Coming to terms with a terminal diagnosis or long term condition can be very difficult. Physical changes can limit people's ability to function as freely and independently as they have been able to in the past. The effects of a condition, treatment and surgery can affect the way our bodies look and feel, which in turn can change how we feel about ourselves and relate to others.

Roles and relationships can change, with partners or friends becoming 'carers' rather than 'Mum' or a husband. Not being able to do as much can lead people to question their value or identity.

Anxiety and fear for the future can be difficult to handle, as can communicating about things to do with dying, death and bereavement.

Counsellors of all kinds, including bereavement counsellors, can help people to come to terms with the changes they are experiencing and offer emotional support. We provide a confidential and safe 'space' where people can speak freely and without inhibition about things that are concerning them and explore ways of coping with loss. Being able to speak openly to someone outside the family and situation can be extremely helpful.

We sometimes work with people before someone has died, in coming to terms with the losses that they have already faced and prepare for life after the person dies. We can offer specialist support, for example to children or people with learning disabilities.

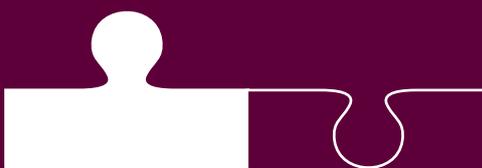
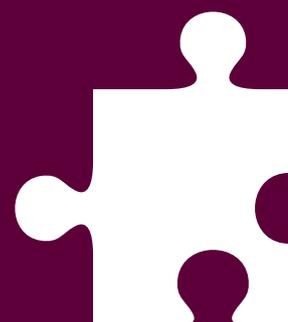
Often our role is to reassure people that there is no right or wrong way to grieve and that their thoughts and feelings are normal and to be expected.

People are often well supported when someone is dying and shortly afterwards, but after the funeral can feel isolated and alone. We can offer support at this time.

We can work with people on a short or longer term basis and are based in a range of different settings, for example, in a private practice (sometimes at home), in hospices, or hospitals. Bereavement support groups and networks can also be helpful.

What I need from others

- referrals
- a good understanding of the situation and the person's particular concerns
- support from colleagues to deal with the emotional aspects of the role.



Hospice worker

What I do

Many different people work in hospices, including doctors, nurses, occupational therapists, physiotherapists, counsellors and volunteers. We are usually trained in the same way as our colleagues in hospitals or the community but have particular training and experience in caring for people who are dying, nearing the end of their life, or bereaved.



How I contribute

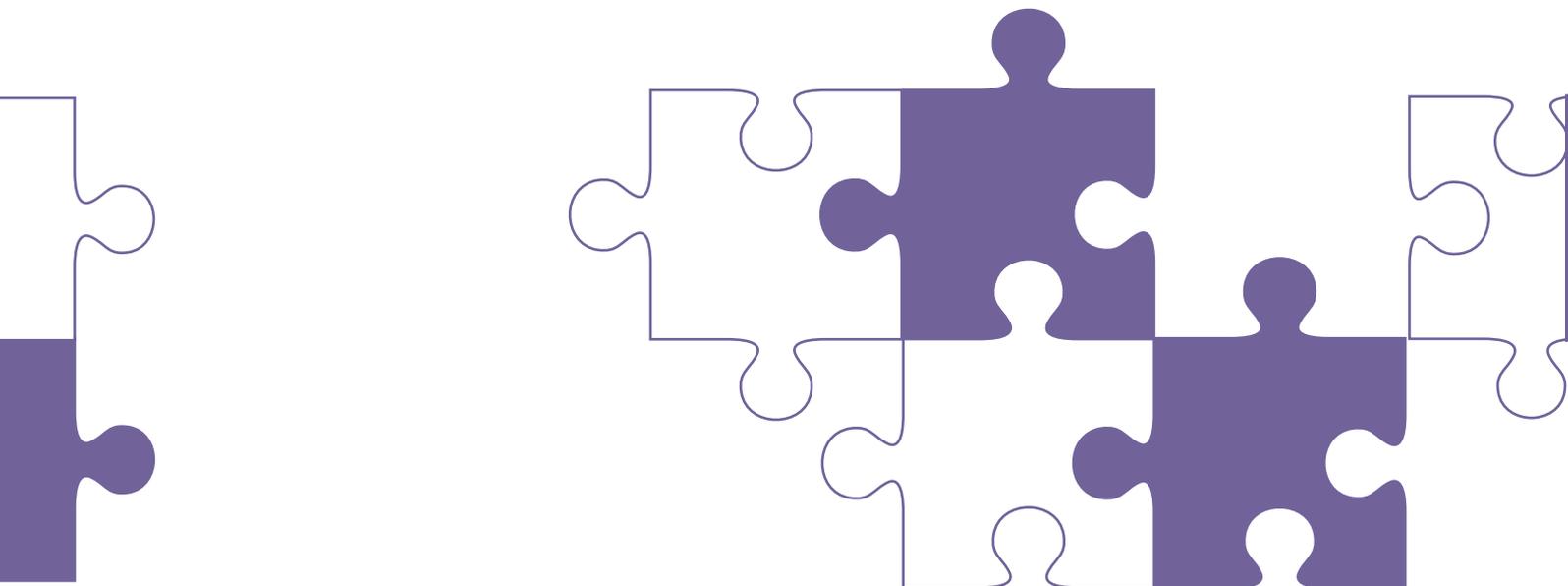
I am a health care assistant in a hospice. My role is similar to my colleagues in hospitals but we generally have more time available and are often able to offer more personalised and physical care as well as spiritual and psychological care. We can take more time because we have more staff than in hospitals and have fewer patients to support.

We care for the physical needs of patients, including washing and dressing them and our highest priority is to maintain as much dignity as possible. Quality of care is very important both to the patient and their family, who will be left with the memory of how the person was cared for.

We listen closely to the patient and their family about how they like to be cared for. For example, some people hate baths but love having a shower.

Sometimes we just sit with patients and their families and chat. There are lots of activities available, as well as special therapies such as massage, aromatherapy and acupuncture. We encourage people to take part if they would like to and support them to do this.

All kinds of things can be important to people as they are nearing the end of their life, in particular spiritual beliefs or faith. Some people like to observe particular rituals such as ablution before eating or attending religious services. We are careful to observe and respect these and support people in carrying them out.





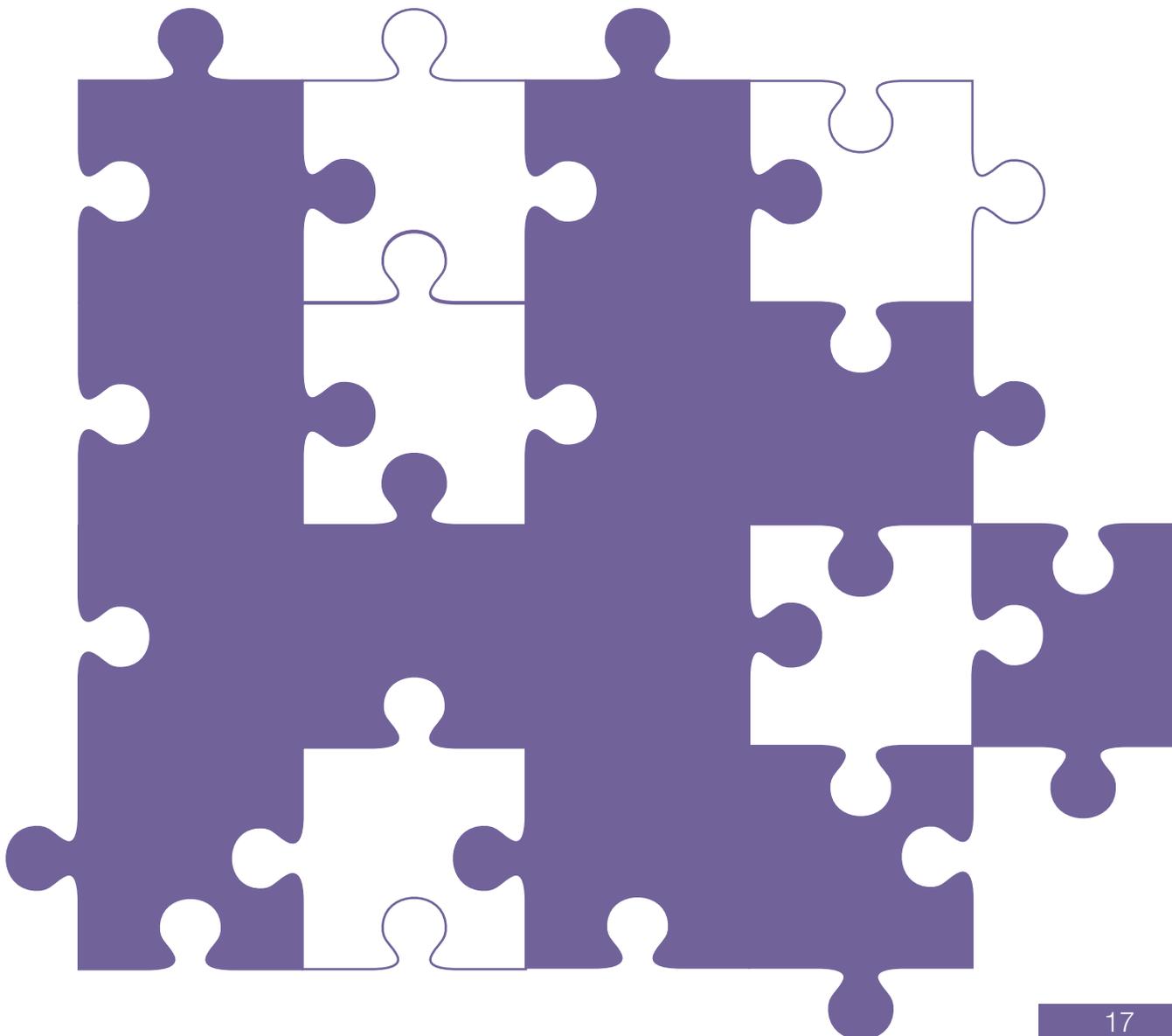
We work with volunteers, providing training so that they can carry out their role. We receive training in both empathy and listening skills so that we can really ‘tune in’ to what the person wants and needs and care for them sensitively and to the highest possible standard.

Sometimes people speak to us about all kinds of things that they are concerned about. I think because we’re not as senior as others, it can feel as though we’re more approachable. If people express particular concerns we will liaise with others in our team to make sure that they receive the support they need.

We get to know people’s likes and dislikes when it comes to food and work with dieticians to make sure that people can eat the food they enjoy and are able to gain the energy they need.

What I need from others

- a supportive team
- good communication between all hospice staff
- for it to be OK to admit you’re not sure about something
- regular team meetings where people can say what they need help with or update other staff about what’s happening with a person receiving care.



Hospice at home nurse

What I do

There are various hospice at home services in different areas. Where I work, I am based at the hospice with all the people who work there but my main role is to go to people's homes and provide support. I am a trained nurse with additional training in palliative care. Hospice at home nurses are sometimes called 'outreach' nurses.



How I contribute

The hospice usually receives referrals from the GP or district nurse, requesting support for people who have a serious or life threatening illness and who would benefit from the extra support we can offer.

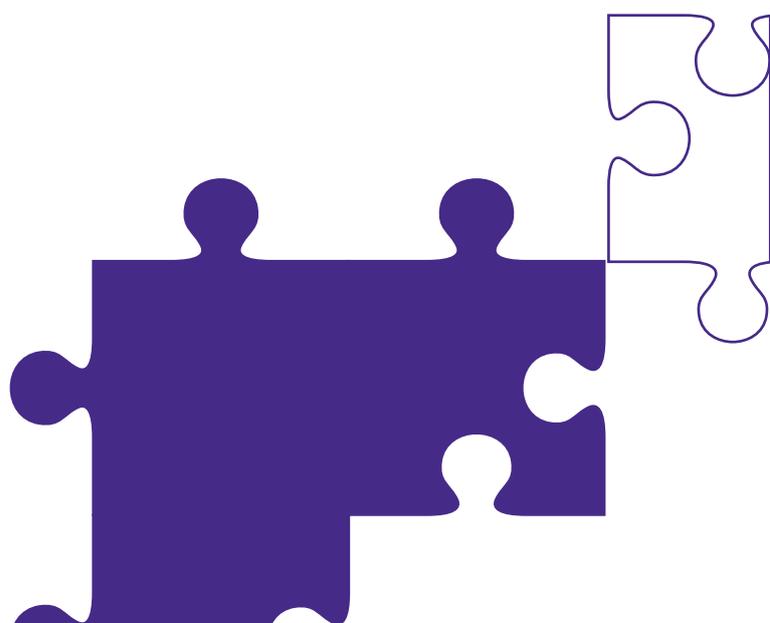
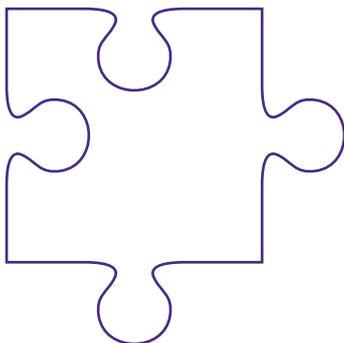
I work closely with people and their families to ascertain where they would like to die. Most people would prefer to die at home but sometimes they request to die at the hospice, so I try to support this wish where possible.

I work as part of a team of specialist nurses and can offer people access to our social workers, doctors, physiotherapists, complimentary therapists and members of the chaplain team. This means that we can look after the whole person and family from a social, physical, psychological and spiritual perspective.

Sometimes the person who is dying has young children and the parents are very anxious about how to prepare them for coping with the changes in the family. I can offer advice and reading on how to deal with these issues and offer access to the psychologist for further support for the whole family.

I am able to offer advice to GPs and district nurses about symptom control and am able to contact doctors or other staff at the hospice for further assistance if needed.

We have a day unit where we can arrange for people to attend, either as a break to relax or to address symptoms that may be causing a problem. We are also able to offer respite care that can help to give the family a rest, knowing that the person is being cared for in a non-hospital but safe and caring environment.



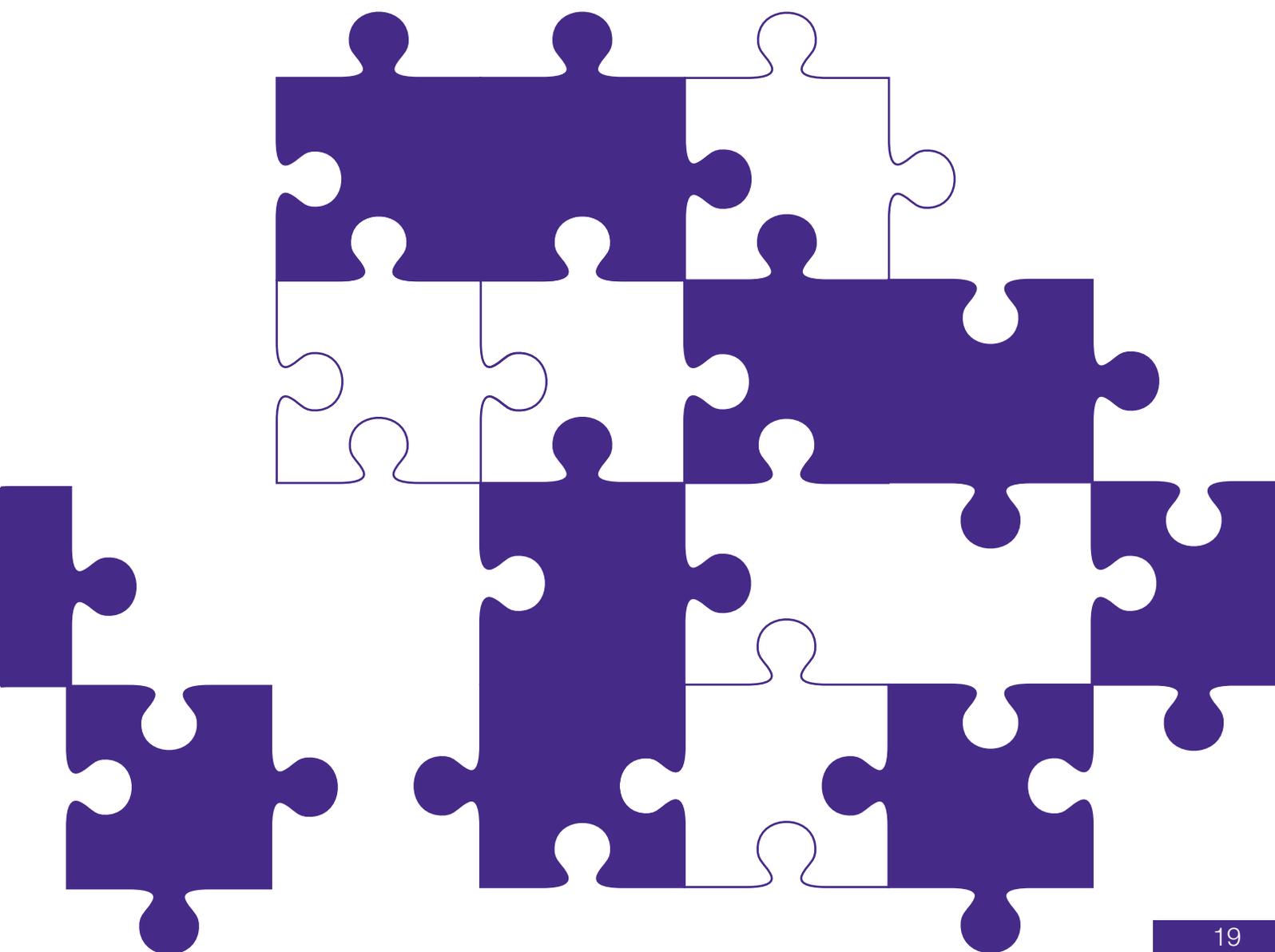


I usually visit the family after the person has died. I can arrange on-going bereavement support through the hospice where necessary. We have a carers group who meet to support each other and make new friends which families and carers find really helpful.

We provide education sessions for community staff and volunteers to attend, usually held in the hospice. We find we can learn together at these sessions, sharing information and ideas. We see ourselves as very much part of the local community where we can help other staff, patients and families to provide good end of life care.

What I need from others

- a supportive team
- good communication between all hospice and community staff
- new staff in the community to be made aware of the hospice and hospice at home service at induction
- for staff to be comfortable about asking for advice and support from our team
- respect of each other and our part to play in end of life care
- regular team meetings where people can say what they need help with or update other staff about what's happening with a person receiving care.



Occupational therapist (OT)

What I do

Occupational therapists work with people of all ages in many places, including the community, hospitals and hospices, to maximise both independence and quality of life.

How I contribute

I work in a hospice and care for patients and their families who use day-services, the in-patient unit and who are in the community. I aim to help people to do what they need and want to do, promoting and maintaining independence as much as possible.

If someone is being discharged from hospital to home, I find out what kind of things they do at home and make sure equipment and support is available. We help people come to terms with needing equipment by describing it as a positive step towards independence and possibly staying at home for a bit longer, rather than a step closer to dependence.

I complement medical interventions by teaching patients, carers and families self-management techniques such as how to manage pain, breathlessness, anxiety or energy levels.

We work with district nurses who can often arrange pressure relieving mattresses and hospital beds if someone is nearing the end of their life. We work closely with physiotherapists, often assessing people together. For example, a physiotherapist may have specialist knowledge about positioning to enable comfort and ease of breathing, but we can help to arrange the right equipment that will facilitate this.

We also work with all other members of the team, including dieticians because people often have low energy, and making sure they have the right nutrition is vital.

We work closely with Lymphoedema specialists (Lymphoedema is a kind of swelling that people with cancer and other serious illnesses can develop) to help support any difficulties with mobility and breathing. We can refer people for reflexology, massage and relaxation either to distract them from anxiety or as a way of managing it.

In end of life care, the way people feel and the things they are able to do can vary hourly and daily. We therefore try to be flexible and pre-empt what could happen to avoid crises. We provide hope and work very sensitively with people, treading the difficult line between not creating dependence too early but at the same time avoiding crises.

What I need from others

- people to understand that our role is much more than providing equipment
- encouraging people to take part in activities and use the support we offer
- communicating, as often computer systems don't talk to each other or tell the whole story
- meeting regularly, face to face, through training and networking
- a commitment to putting politics to one side and being flexible
- being as responsive and timely as possible (although we appreciate the demands on time).

Paramedic

What I do

Paramedics are senior health care professionals with specialist skills in emergency medicine. We usually work in an ambulance service in the community with an assistant or ambulance technician. We respond to emergency 999 calls or may be directed from 111 calls and, in certain circumstances, can be booked ahead of time.

How I contribute

On a day to day basis, we don't tend to come into contact with patients who are near the end of their life. If we do become involved at that point it is because someone felt that the person needed urgent medical care.

We are sometimes required to provide emergency medical care to a person in their own home, depending on their wishes for end of life care. We can administer prescribed medication and have access to high-technological equipment and, depending on the person's wishes, are able to stabilise them in the community. We're also able to provide immediate acute care, such as pain relief in the community if district nurses are not available to help. If the person needs to be taken to a more specialist place of care, it is our job to brief the other medical staff about the person's condition and what has already been done to support them.

We also play a very practical role in end of life care as we can transport people from a place of care to their preferred place of death. People sometimes book or call us out to manually transfer people from their own bed to a hospital bed in their own home.

If we are called out in an emergency or crisis situation, we try to make contact with a GP, district nurse or any specialist staff like hospice doctors or nurses who are known to the patient, to make sure that we are fully aware of their wishes, as it is vital that we have the right information so that we can treat people accordingly. This includes knowing if someone has said they do not wish to be resuscitated, or if they want to remain at home to die.

We provide emotional support and reassurance for both patients and their families, at what can be an extremely stressful time. There are occasions when we don't have access to the information we need and family members can, understandably, feel angry and frustrated. We are trained in advanced communication skills and are often able to diffuse challenging situations. We always try to do the best we can for the patient and their family.

What I need from others

- access to clear, up to date, accurate information such as advance care plans and 'do not attempt resuscitation' forms, to ensure that any care carried out is in accordance with the person's wishes
- responsive support from other professionals who are involved in the person's care
- for members of the public to know how to express and record their wishes in a way that will be taken into account by paramedics.

Palliative care specialist

What I do

Palliative care specialists (also known as consultants) are doctors who have special training and experience in caring for people with life-limiting conditions or who are dying. We work mainly in hospitals and hospices.

How I contribute

GPs or other doctors refer patients to me because they need specialist help with how to care for them and their families. Sometimes I support people on a one off basis or offer advice to the GP, but in other situations I might be involved for a longer period of time. I work in hospitals and hospices, and sometimes people are cared for in specialist palliative care units or wards in a hospital.

There are lots of elements to my role. Firstly, I need to keep up to date with how the patient and their family are feeling and responding to medication or support. To do this, I review their notes, spend time with them and their families and speak to colleagues.

I need to understand what's important to the patient and their family and do all I can to make sure they're supported. This can involve making sure that people who are experiencing distressing or uncomfortable symptoms such as pain or sickness are given treatment to alleviate these symptoms. It can also involve spending time understanding their concerns or wishes for the future and access support from colleagues if I'm not able to provide it myself. If the person would prefer to die at home, I help to arrange the necessary care, support and transport.

One of the main things I try to do is help the patient to feel safe, that they're in the right place and able to live with an illness without it taking over their life. I try to help people to have peace of mind, as much as possible.

Caring for the family and those close to the patient is also my responsibility. They are, understandably, often worried or upset, so my role is to listen, identify whether any additional support is needed and make sure it is put in place. For example, families may have financial worries or need a bit of time out to help them to cope.

The other main aspect of my work is having responsibility for the entire palliative care service. This involves managing the staff and making sure we're working well together to provide the best possible care within the budget available. I make sure colleagues are supported as providing care to people who are dying and their families can be emotional and demanding.

We are always trying to find ways to widen the care we provide, for example, arranging appointments closer to home or with more than one specialist to minimise travelling.

What I need from others

- for everyone to know the person's wishes and be confident in playing their part
- good relationships with colleagues and support from senior management
- people not being afraid to admit when they don't know something or seek help
- to be flexible and respond to unexpected situations that arise
- communication with the rest of the staff and social care/social services.

Pharmacist

What I do

Pharmacists are experts in medicines. We work in hospitals, hospices and the community to promote safe and effective prescribing.

How I contribute

I basically provide the medicines that are prescribed by doctors. I have an important part to play in the process of accessing medication that can relieve symptoms such as pain or nausea.

I work in a hospital that is linked to a hospice, but some of my colleagues work in local, community-based pharmacies.

As people draw near to the end of their life, managing pain and other symptoms and balancing the effects of different medication can become more and more complex.

People often have more than one condition and the effects of medicines can conflict with each other and cause side effects. It can be difficult for families to understand what the various medicines are for and when they should be taken. Therefore, one of my main roles is to give advice to doctors, nurses, patients and their families about the roles of different drugs so that they can have the best possible effect with the least possible side effects.

Many of the drugs used at this time in people's lives are, what we call, 'controlled drugs'; in other words we have to account for each and every pill that we give out. These drugs are not controlled because they are dangerous but because they can be abused, so the authorities keep a very close check on them. There are many regulations associated with prescribing controlled drugs so our role is often to guide doctors about how they can prescribe what is needed, within the tight regulations. A lack of clear guidelines on appropriate prescribing for end of life care can delay treatment which can be distressing and uncomfortable for patients and families.

In hospitals, pharmacists are available at any time of day or night. Although there are some 24 hour pharmacies in the community, they are not always located near the person who is dying and their family, so we often support doctors by helping them to set up 'just in case' boxes containing medicines that might be needed in future. This is sometimes called 'anticipatory prescribing'. My colleagues in the community try to make sure that these kinds of medicines are always in stock to avoid delays in accessing them when they're needed.

We support families and carers who might feel unsure or concerned about the administering medication and make sure that they are looking after themselves too. Our colleagues in the community tend to get to know patients and carers over a long time. They can deliver medications to people's homes and are often a trusted source of support.

What I need from others

- it helps if pharmacists in all settings have had training in appropriate prescribing for end of life care
- for us all to work together to produce clear prescribing guidelines so that doctors are able to prescribe quickly and correctly.

Social worker

What I do

Social workers work with individuals, and their families, to support and enable them to maintain and maximise their independence and wellbeing, balancing the need for managed risk taking and safety. We provide practical and emotional support as well as signposting and referring to other services.



How I contribute

I'm not a specialist in end of life care, but dying is part of life and is an important part of my work. My role is to help people live as well as possible in the time they have left. I work with lots of other people, such as home care staff, GPs and healthcare teams. Sometimes I work with other professionals and organisations important in the person's life, such as housing providers. People are referred to us by GPs, occupational therapists and community nurses, or other professionals because they need help and support with day to day life. Individuals can also self refer.

I assess the person's strengths and needs, taking account of all of the important aspects of their lives, for instance their extended family, or their religious beliefs. My input is shaped around responding to what matters most to them, for example, they might be able to walk a little bit but could benefit from hand rails to steady them when walking around the house or getting in and out of the shower. They might have a dog and need some help with walking it. We can arrange practical support like delivery of meals or for someone to come in and help with hands on care. Or for others it may be putting them in touch with sources of spiritual, faith or religious support. What matters is listening really carefully to what is important to the person and their family.

Families and carers need support too. I can arrange carer's assessments to look at their needs and let them know about any financial help that might be available.

I consider whether individuals or their families may be eligible for any additional funding. We inform them about the kind of support that might be available, the process of applying and can help to fill in applications for funding. Funding is often needed urgently and people's needs can change rapidly, so there can be some pressure in arranging this quickly.

I support families and carers in bereavement too, offering practical advice and signposting them to sources of additional support if needed.

What I need from others

- a close working relationship with the people I am supporting in the community, with colleagues in social and health services, and with others involved in providing support, such as housing providers
- for the family to be completely informed about every aspect of care and to be reassured and supported
- for the person's end of life care wishes to be known and taken into account
- for everyone involved to be working together to give the best possible care
- supportive relationships, as at the end of the day, we're all human and can find situations sad

Physiotherapist (Physio)

What I do

Physiotherapists help people with physical difficulties that impair their ability to live as they would like. We work in all health and care settings including hospitals, hospices and the community and work alongside colleagues to ensure that people are able to be as active as they would like to be.

How I contribute

I work in a hospice so my role is a bit different from community or hospital physios. I work with others in the end of life care team to help improve people's quality of life, enabling them to keep doing as much as they can and would like to do, for as long as possible.

For example, when someone has a life-limiting condition but isn't at the very end of their life, we often give advice about the kind of exercise that might help and make people feel better. We run groups for both patients and their families so that they can support each other, do some seated exercise and sometimes go out or do something slightly more active.

If people have things they'd like to achieve or goals they'd like to work towards, we offer help and support. We can help people to access equipment that may help, such as walking sticks or frames.

We provide non-medical support for symptoms like breathlessness and pain. For example, we can help people to position themselves so that they are comfortable and to minimise the pain they're experiencing. We can support people to deal with the emotional effects of their illness by teaching mindfulness, relaxation or cognitive behavioural techniques, all of which can help people to manage their anxiety.

We support families and carers, particularly with practical aspects of care such as how to move or handle the patient, how to use specialist equipment and ways to change their lifestyle to adapt to new situations.

We work closely with Lymphoedema clinics. Lymphoedema is a kind of swelling that people with cancer and other serious illnesses can develop, often affecting people's mobility and breathing.

If people are being discharged from the hospice or hospital to their home, we work with the discharge planning team to make sure that everything is in place to facilitate independence and quality of life.

What I need from others

- excellent communication between team members so that we all know the situation and what needs to be done
- time - we need to be able to spend time with patients and their families to really understand what's important to them and any concerns they might have. These things can't be rushed
- it's important that other professionals are open to accepting advice and support from others, whatever their role, so that we can enable the best possible outcomes for patients and their families.

Speech and language therapist

What I do

Speech and language therapists (SLT) assess and treat speech, language and communication problems and work with people who have difficulty eating and swallowing.

How I contribute

I work with people of all ages and in all care settings. My particular role is part time in rehabilitation, helping people to regain their ability to communicate, for example, if they have had a stroke, and part time at a hospice, supporting people who are nearing the end of their life. This is a unique role, although speech and language therapists are often closely involved in people's care as they draw near to the end of their life.

The two main aspects of my work, whatever the person's condition or how near the end of life they are, are to help people to swallow and communicate. We do this by providing a professional assessment and then offering advice or guidelines along with helping people to prepare for what might happen in the future.

For example, someone with a life-limiting condition or long term progressive illness like Motor Neurone Disease or dementia may, at some point, lose their ability to swallow or communicate. A swallowing difficulty not only affects the ability to eat and drink but can also cause people to cough and choke when eating. This is uncomfortable and unpleasant and increases the risk of food or drink 'going down the wrong way', ending up in the lungs and potentially causing chest infections.

We try to sensitively explain what could happen in the future and how people might be able to prepare for it. Initially this may involve, for example, suggesting different ways of eating, better positioning so that it is easier to swallow and possibly a different pace of eating. If things became more difficult, we might explain other possible ways of gaining nourishment such as 'PEG feeding' (Percutaneous endoscopic gastrostomy) which is essentially a tube allowing nutrients to be given directly into the stomach.

We might help to create communication aids so that people can express themselves more easily, perhaps using symbols or non-verbal ways of communicating.

As people draw near to the very end of their life, we focus on comfort and quality of life, and ways of making eating and drinking more pleasurable and less uncomfortable. If they do not wish to eat or drink, we advise how to provide mouth care for comfort and to avoid infections.

We work closely with physiotherapists, dieticians, nurses, care assistants, doctors and occupational therapists, often carrying out joint assessments.

What I need from others

- for those who assist with eating and drinking to follow guidance provided and let us know about any difficulties or changes
- to be able to work closely together, for example doing joint assessments.

Spiritual, faith and religious support

What I do

Spirituality, faith and religion mean different things to different people. They can include many things including making sense of our place in the world, the meaning of life, and our beliefs about an afterlife. Whether we have a faith or not, our beliefs profoundly affect the way we live, our relationships and how we respond to the world around us.

How I contribute

I'm a chaplain, but it's important to remember that a chaplain's role is just one way of providing spiritual support. More are described below. Many people think that chaplains only provide support for people who are committed Christians and that if people do not follow this faith, that we will encourage them to do so. That is not the case. Chaplains support everyone, regardless of their spiritual or religious beliefs. We work closely with a wide range of people from different faith, religious and non-faith communities.

Trying to make sense of and accept what is happening now, what may happen in the future and what happens after people die can be extremely troubling. Concerns and questions about these aspects of life can sometimes feel more painful than anything else, and can cause physical symptoms such as agitation or reduced appetite.

There are many ways of supporting people's spiritual needs. Sometimes this is through religious faith, such as Judaism, Islam or Christianity. If a person has a religious faith there may also be rituals attached to the process of death and dying, and these need to be understood, respected and acted upon by everyone who is providing care and support. Religious leaders may be important in offering comfort and support to the person who is dying and their family. They can also offer advice and give information to others about the ways in which the person should be treated both during and after death.

Not everyone has a religious belief, but this does not mean they have no spiritual needs. Support can be given in many different ways, for example; through counselling, meditation, or being with friends. For others, their spirituality is a private matter. However people view or express their spirituality, this should be acknowledged and respected by the people providing their care and support.

Whilst there are some people whose particular role is to provide spiritual support, like chaplains and spiritual, faith or religious leaders, everyone can play a part in supporting people's spiritual needs. Spiritual matters, however you might describe them, can come up in conversation with anyone including district nurses, GPs, social workers, volunteers and cleaners.

Those with a specific role in spiritual support are often involved in training colleagues in how to assess and respond to people's spiritual needs.

What I need from others

- to be told who needs spiritual support
- for people to understand that chaplains are not just about religion or for calling at the very end of someone's life, we're there for anyone at any time
- support from my colleagues. better care.

Who to call when and how to contact them

This form can be adapted to provide a useful, easy-to-access record of the different people involved in someone's care and how to contact them.

Role	When to call them	Local contact details
Commissioner		
Dietician		
District (Community) nurse		
Domiciliary care worker		
Funeral director		
General practitioner (GP)		
Grief/bereavement counsellor		
Hospice worker		
Occupational therapist		
Palliative care specialist		
Pharmacist		
Physiotherapist		
Social worker		
Speech and language therapist		
Spiritual support/faith leader		

Glossary

Palliative and end of life care

There is no universally agreed definition for what 'palliative' and 'end of life care' mean, but these definitions might be helpful.

End of life care

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- a) advanced, progressive, incurable conditions
- b) general frailty and co-existing conditions that mean they are expected to die in within 12 months
- c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- d) life-threatening acute conditions caused by sudden catastrophic events.

Palliative care

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor 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
- enhances 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 and includes those investigations needed to better understand and manage clinical complications.

Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

Further information can be found at www.who.int/cancer/palliative/definition/en.

These definitions are taken from 'One chance to get it right: Improving people's experience of care in the last few days and hours of life, published by the Leadership Alliance for the care of dying people, 2014' www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Spirituality and spiritual care

Spirituality

This is difficult to define but relates to the need we all have to make sense of the world and our experience of it. The 'soul' or 'spirit' creates internal resources that can sustain, motivate and transform an individual's experience of life. A common misunderstanding is that spirituality and religion are synonymous. Religion is actually a belief system linked to rituals and practices that may lead to an increase in spiritual understanding. Spiritual needs common to all are the need for love and meaning. Kindness, compassion and deep listening are the core skills for providing spiritual care and are those most appreciated by patients and their families.

Spiritual care

This type of care recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires.

(NHS Education for Scotland, 2009)

Understanding cultural, religious and spiritual perspectives on dying, death and bereavement
Whilst there have been books, courses and websites describing different cultural practices published, it is vital to remember that wide variations can exist even within different cultural, ethnic, spiritual and religious communities, and that people's views and practices can change, especially as they draw nearer to the end of their life.

It is therefore more important to ask the person you are caring for what matters to them than to try to develop a deep understanding of every faith, spiritual and non-religious belief.

Dying Matters worked in partnership with Heart of England Foundation Trust and Flix Films to produce a film which aims to improve understanding of Muslim traditions and practices among doctors, nurses and other health and care professionals. It was developed with Birmingham Central Mosque and the Birmingham Muslim Burial Committee. For more information, visit: www.dyingmatters.org/news/dying-matters-launches-groundbreaking-muslim-film

Useful links and resources

The film that complements this booklet is available to view on the Skills for Care website www.skillsforcare.org.uk/endoflifecare and is also called '[Understanding roles – working together for better end of life care.](#)'

Skills for Care has a number of fantastic resources which aims to increase awareness and understanding of the importance of working together to support people at the end of their lives. This includes a film called '[it helps to talk](#)' which is a powerful film about a person with Motor Neurone Disease who conveys her end of life wishes to her son and sister. It depicts how a breakdown in communication between front line workers can cause unnecessary stress and upset to everyone involved. The film is part of a training pack for all front line workers.

Support for health and social care professionals

Skills for Care ensures that England's adult social care workforce has the appropriately skilled people in the right places to provide high quality social care. www.skillsforcare.org.uk

Skills for Health is the Sector Skills Council for health. They help the whole UK health sector develop a more skilled and flexible workforce. www.skillsforhealth.org.uk

The Royal College of GPs is the academic organisation in the UK for general practitioners (family doctors). It aims to improve the standards of care which patients receive in general practice www.rcgp.org.uk

The Royal College of Nursing represents nurses and nursing, promotes excellence in practice and shapes health policies www.rcn.org.uk

The Queen's Nursing Institute is a registered The Queen's charity dedicated to improving the nursing care of people in their own homes www.qni.org.uk

The Social Care Institute for Excellence provides a UK resource of good practice and knowledge aimed at improvement of social care services with focus on the central role of people who use services www.scie.org.uk

The British Association of Occupational Therapists and College of Occupational Therapists is the professional body for occupational therapists and OT staff in the United Kingdom www.cot.org.uk. For information about specialist palliative care occupational therapy visit www.cot.co.uk/cotss-hiv-aids-oncology-palliative-care/cot-ss-hopc

The Allied Health Professionals Federation provides collective leadership and representation on common issues that impact on its member professions www.ahpf.org.uk

Palliative and end of life care

The National Council for Palliative Care works to improve palliative and end of life care for all who need it www.ncpc.org.uk

Dying Matters is a broad based national coalition which seeks to change public attitudes and behaviours towards dying, death and bereavement www.dyingmatters.org

Hospice UK supports the development of hospice care in the UK www.hospiceuk.org

Expressing and recording wishes for the end of life

Preferred priorities for care:

www.nhs.uk/resource-search/publications/eolc-ppc.aspx

Support for different conditions

Marie Curie Cancer Care is a UK charity dedicated to the care of people with terminal illnesses. They are best known for their Marie Curie nurses, who provide care to terminally ill patients and their families in their own homes or in hospices, while offering support to their families www.mariecurie.org.uk

Macmillan Cancer Support provides support for people with cancer, from diagnosis, to treatment and beyond www.macmillan.org.uk

The Motor Neurone Disease Association (MND) funds and promotes global research into MND and provides support to people affected by Motor Neurone Disease www.mnda.org.uk

The Multiple Sclerosis Society funds research, gives grants, campaigns for change, provides information and support, invests in MS specialists and lends a listening ear to those who need it www.mssociety.org.uk

The British Heart Foundation is the UK's number one heart charity www.bhf.org.uk

The British Lung Foundation supports people affected by lung disease, promotes greater understanding, campaigns for changes in lung health and funds research so that new treatments and cures can save lives www.blf.org.uk

Support for carers

Carers UK gives carers expert advice, information and support. They campaign and innovate to find better ways to reach and support carers www.carersuk.org

The Carers Trust provides information, advice, discussion and support for carers www.carers.org

Co-ordinated/integrated care

The benefits of Electronic palliative care co-ordination systems (EPaCCS) www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care/benefits-of-epaccs.aspx

Further information about Electronic palliative care co-ordination systems (EPaCCS) www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care/epaccs-resource-library.aspx#sthash.Ra7MKAAK.dpuf

An example of an Electronic palliative care co-ordination system
Co-ordinate my care www.coordinatemycare.co.uk

Grief/bereavement support

The Bereavement Advice Service supports and advises people on what to do after a death www.bereavementadvice.org

What to do after someone dies describes the three things that must be done in the first few days after someone dies www.gov.uk/after-a-death/overview

The 'Tell us once' service allows people to report a death to most government organisations in one go. Most councils run this service www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once

The British Association of Counselling and Psychotherapy is a professional body representing counselling and psychotherapy with over 40,000 members and works toward a better standard of therapeutic practice www.bacp.co.uk

Cruse Bereavement Care offers support, advice and information to children, young people and adults when someone dies, and aims to enhance society's care of bereaved people www.cruse.org.uk.

The Compassionate Friends supports bereaved parents and their families after a child dies www.tcf.org.uk

Funerals

Your funeral choice is committed to offering free, independent advice on funeral directors costs and funeral and cremation options in people's local area www.yourfuneralchoice.com

The good funeral guide is an independent, not-for-profit information resource which aims to help people arrange the funeral they want www.goodfuneralguide.co.uk

The natural death centre is a social, entrepreneurial, educational charity that gives free, impartial advice on all aspects of dying, bereavement and consumer rights www.naturaldeath.org.uk

Funeral adviser is a not-for-profit social enterprise aimed at supporting people to find the right funeral director for them. They are completely independent of the funeral industry www.funeraladvisor.org.uk/

Spiritual support

An example of a hospice chaplaincy service

www.stjohnshospicedoncaster.co.uk/services/spiritual-religious-care/

Further information about spiritual support

www.ncpc.org.uk/spiritual-support

The association of hospice and palliative care chaplains exists to promote good standards among chaplains involved in the pastoral and spiritual care of people (including carers) facing death from life threatening illnesses www.ahpcc.org.uk

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