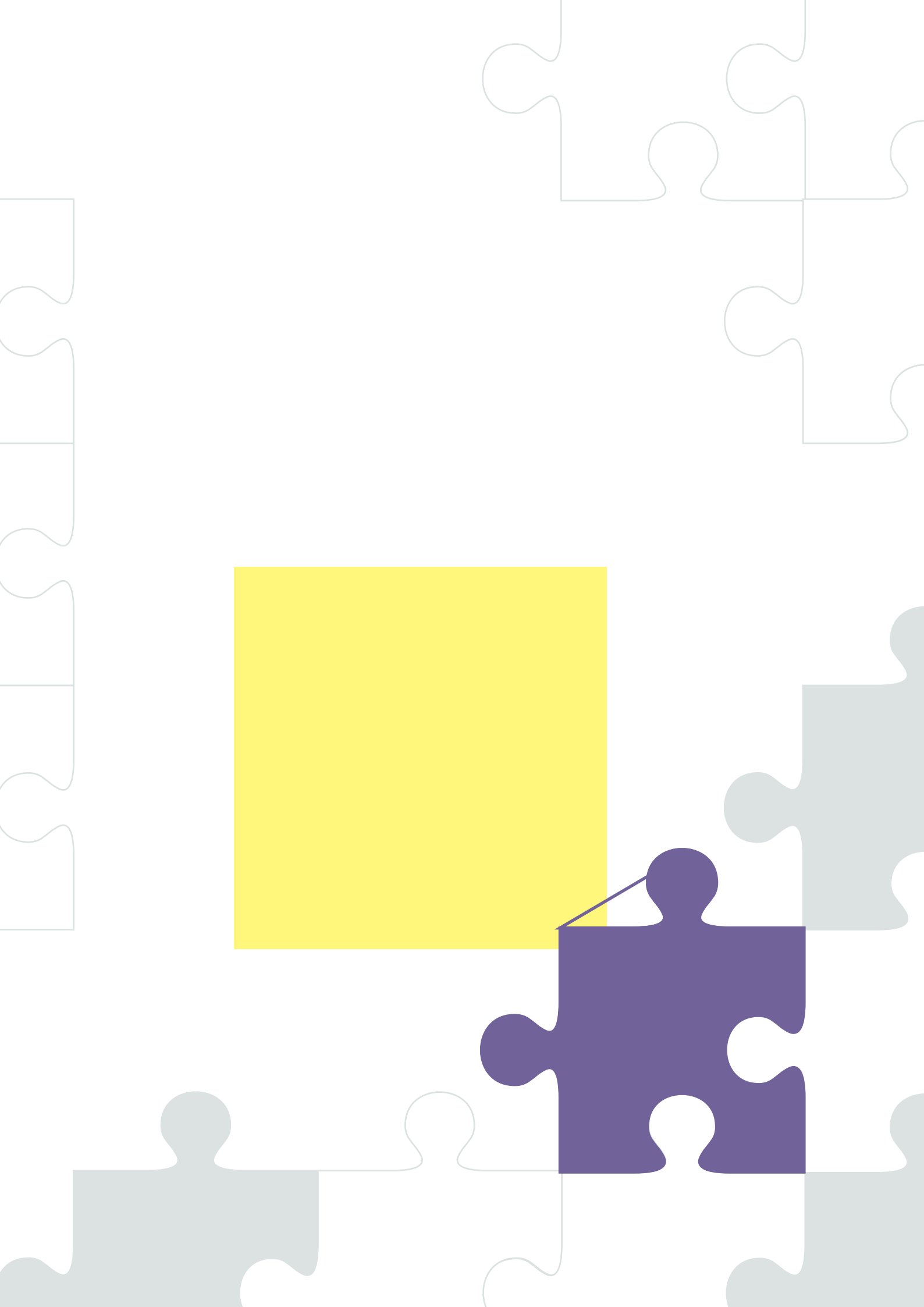
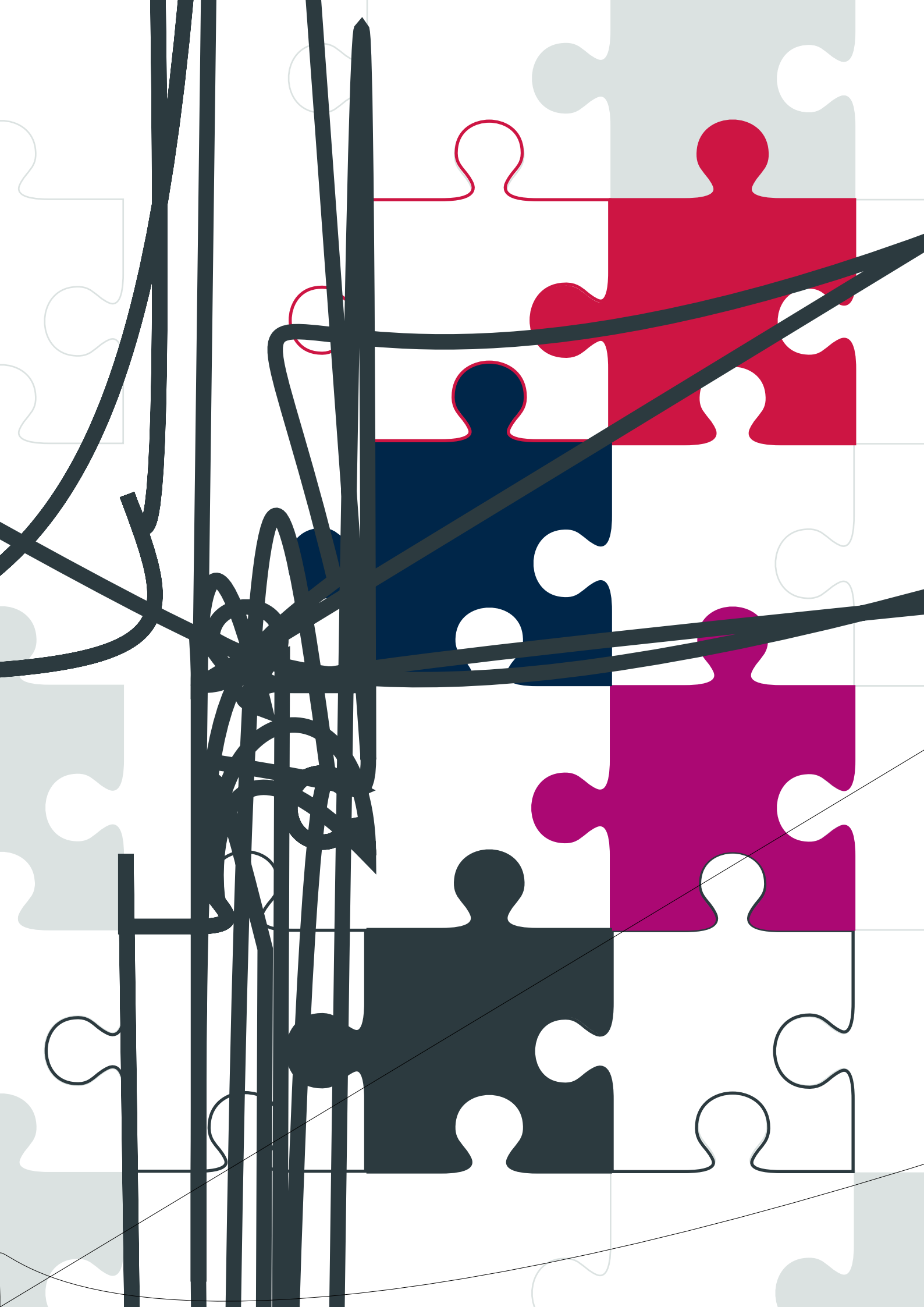


Великий и могучий русский язык  
наши дети изучают с раннего детства.  
С помощью родителей и учителей  
они познают красоту и богатство  
нашего родного языка.







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/endo\\_lifecare](http://www.skillsforcare.org.uk/endo_lifecare).

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.







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



## 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.





### 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 dislikes, 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



### 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 (carers) of (family)





### 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 con ned 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



### **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.



### **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



### 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

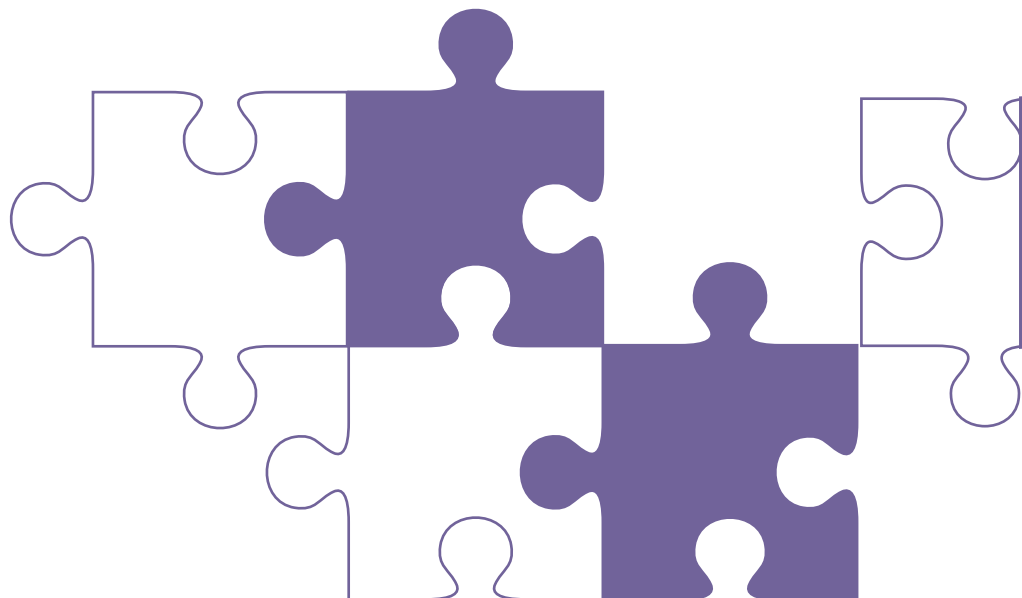
I am a health care assistant in a hospice. My role is similar to my colleagues in hospitals but we generally have more time available and are often able to offer more personalised and physical care as well as spiritual and psychological care. We can take more time because we have more staff than in hospitals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









### 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.

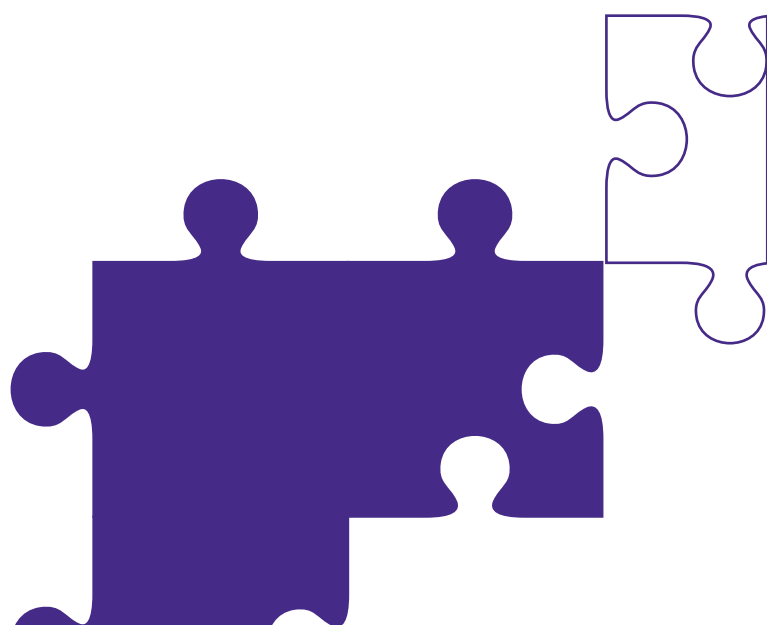
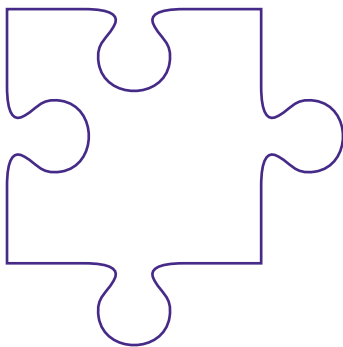
I work closely with people and their families to ascertain where they would like to die. Most people would prefer to die at home but sometimes they request to die at the hospice, so I try to support this wish where possible.

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.









### **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**

- v 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
- v responsive support from other professionals who are involved in the person's care
- v 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.



### 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

GGo



### 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.









### 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.
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## 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](http://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](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)



## Spirituality

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## Additional resources

An example of a hospice chaplaincy service

[www.stjohnshospicedoncaster.co.uk/services/spiritual-religious-care/](http://www.stjohnshospicedoncaster.co.uk/services/spiritual-religious-care/)

Further information about spiritual support

[www.ncpc.org.uk/spiritual-support](http://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](http://www.ahpcc.org.uk)

## Acknowledgements

With grateful thanks to all who described their roles to inform this guide.



