



# End of Life Care

## Learning Resource Pack

Information and Resources for housing,  
care and support staff in extra care housing.

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The National End of Life Care Programme and Housing 21 are happy for other organisations to tailor this resource pack to their specific needs but please acknowledge the source material in any documents produced which use this resource pack as a basis.

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# 1

# Introduction and Overview

This resource pack is designed for anyone who is caring for or giving support to someone with a life limiting condition in an extra care housing setting. This includes people with any chronic condition such as heart failure or respiratory problems as well as people with dementia. Many people develop general frailty and other health problems as they get older.

The idea for the resource pack was a recommendation from extra care housing staff who took part in a service improvement project that Housing 21 and the National End of Life Care Programme jointly undertook in 2008. The evaluation report made it clear that there was a need to improve the knowledge and skills base of staff.

The pack is intended to be a practical tool which gives useful information and guidance. It offers advice on simple things that staff can do, questions that should be addressed and helps to identify how and when to access specialist help. The resource pack will be updated annually. Much of the information contained is generic and will be relevant to extra care schemes in different

localities. However some information will inevitably be area specific, for example local contact details for health and community care teams. Where locally specific knowledge is needed, guidance in this pack will help you to find out the relevant information. Think of it as a kind of “sat nav” to help you and colleagues find your way. The pack also contains details on important terminology concerned with end of life care and specialist health matters.

## **Q When should we think about ‘end of life care’?**

It is difficult to predict when people are considered to be approaching the last 6–12 months of their life, but there are some ways to work with colleagues in health to improve recognition of people who are approaching the end of life and consider very important issues that should be addressed at this time.

Although all of us will at some point die, the type of death will vary for each of us. There is a need to make sure those individuals and their carers are supported during the stages leading up to and during death. Death is not just a physical reality, but a social event too and it is important to address the emotional, social and spiritual needs of people and their families.

Providing effective, high-quality care for someone during the end of their life is a highly skilled role and a challenging one. Without support and information, staff and carers can find the experience overwhelming. This resource pack is intended to help you to deal with the challenges of supporting someone who is dying and to identify how and when you need to access specialist support from health professionals and other

organisations. Managers in each extra care scheme are asked to keep local contact details up to date so staff can rapidly access advice and support.

This resource pack has been piloted with a range of staff in different extra care settings so that we can ensure that it is fit for purpose. If you would like to offer any comments or feedback which will improve future editions then please contact [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).

### **Top tips** *Always remember...*

It is very important to look after yourself as much as possible.

It can become very difficult for a team to continue to function well when there are extra demands put upon it and this can happen if the person you are caring for is in the latter stages of their illness.

Some people within the team will have different strengths than others, use this to determine who does what, sharing out the extra work accordingly.

If someone actively requests not to do or to do a specific task try to accommodate this. However let the rest of the team know why, without breaking any confidences. Try not to let small concerns turn into larger issues.

The main thing is that professionals and carers can become emotionally involved, especially if they have been working with the person for a long time. This is human nature and must be acknowledged, understood and acted upon.

Communication is key: there should be clear and obvious routes where the carers can go for support. This may be through supervision; it may be having a chat with a colleague over a cup of coffee or via a more formal session with a manager, Macmillan nurse, counsellor or member of the clergy.

## 2

# Directory of key contacts in your locality

This section will provide contact details about local services and professionals who can help in the delivery of End of Life Care. This should be completed by court/scheme managers or senior care or support staff.

Details of Professionals or services	During Normal Working Hours (Mon-Fri 9–5pm)	Evenings, Weekends and Bank Holidays
Advocacy Services		
Benefits Advice		
Bereavement Support Organisations		
Carer Centres/Support		
Community Matrons		
District Nurses <i>May be based at various locations e.g. clinics or health centres</i>		<i>Please ring your local surgery for details</i>
Equipment Store		
Homecare		

Details of Professionals or services	During Normal Working Hours (Mon-Fri 9–5pm)	Evenings, Weekends and Bank Holidays
Local Funeral Director(s)		
Local GP surgeries		
Local Hospice number(s)		
Local Hospital number(s)		
Marie Curie (Nurselink)		
NHS Direct	0845 4647	0845 4647
Others		
Pharmacy		
Registrar		
Specialist palliative care team <i>This may include Macmillan Nurses, Palliative Care Consultants, Hospice at Home, Palliative Social worker</i>		
Social Services		
Urgent Care centres/ practitioners		

# 3

## People and services who can help in the delivery of End of Life Care

### Relationships

Relationships always play a very important part in our lives and when caring for someone at the end of life these can come under a lot of extra strain.

You are likely to come into contact with a number of health and social care professionals where relationships are built up as well as the relationships that you will develop with family members, your team members and of course the person you are caring for.

Sometimes it is helpful to develop these relationships as a partnership and working together as a team will help you and the person you are caring for get the best care at a difficult time.

### Working with professionals

- Remember that health professionals don't always have all the answers.
- Try to find out as much as possible about everyone's role so you can seek help from the right person straight away when you have a question or problem. Keep their contact numbers on the list at the front of this guide.
- It is also helpful to have realistic expectations about what they can do for the person you are caring for.
- If you can, give them as much up to date information as you can about the situation.
- If you are concerned about changes in a person's condition or a worsening of their symptoms seek help straight away; don't wait until the end of the week as most departments close over the weekend.

Remember health professionals are human too and a smile or a thank you can always help in many situations.

### Difficult decisions

When the person you are caring for is in the latter stages of his/her illness you may be asked to help make important choices or decisions about their future care.

- This discussion could be about whether a certain treatment is given in a particular circumstance.



- This can be called an advance decision and is often about the decision to refuse treatment if the person's condition worsens, the heart stops or breathing stops.
- It might be decided that the doctors and /or others should not try to resuscitate ("re start the heart") of the person.
- The doctors can write in the person's notes or records specific instructions about the advance decisions made so everyone is aware and respects them.

It is very important to have all advanced decisions to refuse treatment appropriately documented in the person's notes to let people know that this exists. Sometimes a specific form will be used, however this will be dependant on the decision. Such decisions should be communicated with everyone who needs to know.

- It is essential to have honest and open discussions with all involved so that everyone understands the reasoning that goes with every decision.

For further information download guidance 'Advance Care Planning' and 'Planning for your future care' from [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).

## Teamwork

Caring can be physically and emotionally hard work. If you have been looking after an individual for some time you may begin to feel drained. You may have a lot of intense emotions and it may begin to "take over your life." It is important to recognise any signs that this may be difficult for you. You also need to look out for your colleagues.

Many people are also dealing with situations in their personal lives that may impact on their ability to cope with caring for someone at the end of their lives. If you are aware that this may be difficult for yourself or any colleagues speak to your manager who can arrange your workload. Never underestimate the support you can all provide for each other by having a cup of tea and a chat. This type of caring can also be immensely rewarding and satisfying when you see that someone has been well cared for until the end of their life.

## Advocates

Many people in society for one reason or another can become disempowered to such an extent that they are unlikely to be able to fulfil their basic human needs or demand their basic human rights. An advocate can help these people to become active members of society and ensure that the person's voice is heard.

### The main themes of advocacy:

- Safeguarding people who are vulnerable and discriminated against or whom services find difficult to serve.
- Empowering people who need a stronger voice by enabling them to express their own needs and make their own decisions.
- Enabling people to gain access to information, explore and understand their options and make their views and wishes known.
- Speaking on behalf of people who are unable to do so for themselves.

### How they might help at the end of life:

- Help in difficult decision making discussions.
- Help with legal issues. Independent Mental Capacity Advocate (IMCA).

### How to find an advocate:

- Contact your local citizens advice.
- Speak to your social worker/care manager.
- Speak to your organisation.

## The District Nurse

District nurses play a crucial role in the primary health care team. They visit people in their own homes providing care for patients and support to family members. District nurses provide a 24hr service dependant on the patient's needs.

### How can a district nurse help in End of Life Care?

- Help to avoid admissions and readmissions to hospital, working with hospital and community teams to ensure patients can return home as soon as they are well enough or when a decision has been made that an individual is to die at home.
- Assessment of patients needs, then in discussion with the patient/family/care staff decide what support is required.
- Assess, plan, implement and evaluate an individuals care/treatment, enabling treatment/support to be modified as necessary.
- Supply medical equipment i.e. bed, mattresses etc for home care as recommended in assessment.

- Recommend a Marie Curie registered nurse or Marie Curie Healthcare assistant depending on the patient's needs.
- Deliver palliative care interventions i.e. pain/symptom control monitoring and evaluation.
- Give psychological support to patient's and their families and carers.
- Offer support in bereavement.

### How can you find a district nurse?

#### *Contact your local GP practice*

District nurses are based within all GP practices, your local practice will advise on district nurse referral/support for people in your care.

Referral to the district nurse is usually via the GP or other healthcare teams.

## Discharge Planning Teams

Normally based in hospitals and are often made up of nurses and social workers. They usually become involved in planning safe discharges from hospital and ensuring there is adequate care and support for individuals when they leave hospital. They need to receive a referral from ward staff to become involved when someone is due to go home. It is sometimes helpful for Court Managers to meet with Hospital discharge teams to discuss any concerns they have about tenants being sent home from hospital.

## The Macmillan Nurse

Macmillan nurses are people who have additional training which gives them expertise in pain/symptom management and in providing emotional support for patients, their families and carers. Additional specialist services from Macmillan Nurses will vary across the country. For example, within the Northumberland team there is a nurse who is specifically trained to care for people with Learning Disabilities who have been diagnosed with a life threatening/life limiting disease.

### How a Macmillan Nurse can help in End of Life care:

- Macmillan Nurses work closely with GPs, district nurses and other health care professionals to help in providing pain/symptom control, guidance and support for patients, their families and carers at any time in their illness, from the point of diagnosis to death.

### Macmillan Nurses can help with:

- Providing assessment, monitoring and evaluation of pain/symptom control.
- Refer individuals to specialist palliative care services if necessary i.e. hospice services, day hospice care.
- Co-ordinate an individual's care through working closely with primary care teams and others involved in the patient's care.
- Offering active support to patients, families, carers, colleagues and professionals, including the provision of education and training.
- Offer support in bereavement.

- Any individual with a life limiting/life threatening disease can be referred to the Macmillan nurse.

### Who can refer?

- Anyone.

### When/why you might refer:

- Support at diagnosis.
- Pain/symptom management.
- Help with investigations and treatments.
- As a resource for advice information.
- Psychological support.

## Marie Curie Nursing Service

Many people who have long term conditions and other serious conditions may wish to make plans for their future care. The Marie Curie Nursing Service can provide high quality nursing care for people in their own homes – this includes extra care and sheltered housing – when they are approaching end of life. Many people feel it is important to be cared for in their own homes at this time. If extra support and care is needed to allow people to be cared for at home, your District Nurse can arrange to have additional help and care.

## Dietician

A dietician is a health care professional who can provide practical information about food. They work with people to promote nutritional well being, prevent food related problems and treat disease and ill health. Dieticians work in a variety of settings including hospitals, health centres, schools and GP practices and also can visit people in their own homes.

### How they may help in end of life care:

- Advice about the quantity of food most suitable for the person.
- Advice about the most appropriate type of food for the person.
- Advice regarding the best consistency of food offered.
- Advice on the type and timing of meals offered e.g. “little and often”.
- Advice/suggestions about the food and drink people can take safely.
- Advice when people use non-oral methods of eating and drinking.
- Liaise with other professionals.

### How can you find a Dietician?

- Speak to your GP.
- Speak to your care manager/community nurse/community team.
- Contact your local hospital.

## Social workers

Social workers can provide emotional and psychological support especially at difficult times in people’s lives. They aim to see the individual as the “expert” and, using a person centred approach, offer support with no judgement value. They can act in a care management role as well.

### How can they help?

- Assessments.
- Liaise with other professionals.

### They can facilitate:

- Social inclusion.
- The person’s rights.
- The person’s choice.

- The individual’s views.
- All done with respect for the individual.
- Help the individual complete a person centred plan.
- Support the individual and their families and/or carers.

## Physiotherapist

A physiotherapist is a health care professional who is concerned with human function, movement and helping people maximise their abilities. Physiotherapists do far more than fixing muscle and joint problems and sports injuries although that is most people’s perception of the role. They assess and treat people with physical problems caused by accident, ageing, disease or disability by using physical approaches.

Physiotherapists work in a variety of health settings including hospitals, health centres, GP practices, and also visiting people in their own home.

### How they may help in end of life care:

- Assessment of physical abilities.
- Posture management.
- Mobility issues.
- Balance problems.
- Chest therapy.
- Assessment of position in specific situations e.g. mealtimes.
- Assessment for specialist equipment e.g. wheelchair.
- Moving and handling advice.
- General advice.
- Liaise with other professionals.

### How can you find a physiotherapist?

- Speak to your GP.
- Speak to your care manager/community nurse/community team.
- Contact your local physiotherapy department.

### Occupational Therapist (OT)

An occupational therapist is a health care professional who can help an individual who has a physical, psychological or social problem that interferes with their ability to carry out normal everyday activities. They assess, rehabilitate and treat people using purposeful activity and occupation to promote independent function. Their aim is to enable people to achieve as much as they can for themselves.

Occupational therapists work in a variety of settings including hospitals, health centres, and GP practices and also visit people in their own homes.

#### How they may help in end of life care:

- Assessment of abilities.
- Give advice on how the home environment can be changed.
- Helping people learn how to do things as their abilities deteriorate.
- Adapting materials and/or equipment e.g. adapted cutlery.
- Reminiscence therapy.
- Life history work.
- Multi-Sensory work.
- Assist the individual with social/psychological issues such as low self-esteem, decreased confidence, coping skills.

- Reality orientation therapy.
- Liaise with other professionals.

### How can you find an Occupational Therapist?

- Speak to your GP.
- Speak to your care manager/community nurse/community team.
- Contact your local Occupational department.

### Community Matrons

Community Matrons are highly skilled nurses who coordinate care and services for people with complex needs, which may reduce admissions to hospital by supporting them at home.

Community Matrons will visit adults who have multiple long term conditions like diabetes, respiratory diseases and heart disease. They aim to help people manage their health condition at home rather than going to hospital. At times people may need to be admitted to hospital for extra support and treatment. If people are admitted to hospital they can coordinate support for them at home and allow people to leave hospital sooner.

#### Will all people with long term conditions have a Community Matron?

No, only people who have been referred to the Community Matron Service by the other professionals who are looking after them.

### What does the Community Matron do?

- Assess the needs of the person and their family.
- Coordinate the care they receive and help identify if extra services or support is needed and make referrals to the other services.
- Educate patients, carers, and care staff about managing long term conditions.
- Help develop plans about how to manage acute situations.
- Develop a personalised care plan with individuals, their relatives and carers and share this with health and social professionals.
- During each visit they review medicines and symptoms and arrange for alterations to be made if necessary.
- They can help people make an advance care plan about their care preferences.

### How would I get in touch with a Community Matron?

Your local Health Centre or GP surgery will have the contact details. People are normally referred to Community Matrons by the following:

- GP
- District Nurse
- Practice Nurse
- Accident & Emergency Department Consultants
- Specialist Nursing Teams
- Social Services.



# 4

## Medication Issues

### Important

You should refer to your organisation's specific medication policy. However, this section contains some useful information about the types of medication that may be used to help relieve pain and other symptoms and the different ways that medication can be given.

### How can medicines be given?

Medication can be administered via several routes and come in many different forms such as:

- **Tablets:** Many people find it difficult to swallow tablets and if care staff notice that someone is having difficulty or tablets are being chewed you should advise the health care team looking after the person.
- **Liquids:** Sometimes easier to take but can taste unpleasant. You can advise tenants to have a flavoured drink after medication.
- **Patches applied to the skin:** these can remain in place for several days and the medication is absorbed via the skin.
- **Injections:** usually given by nursing staff.
- **Medicines for pain and other symptoms** can also be given via a small portable pump (a syringe driver): a fine needle with tubing attached is inserted just under the skin of the abdomen or arm;

this is then attached to the pump. This is useful when someone is unable to swallow and also avoids the need for frequent painful injections. It also allows continual management of symptoms over a 24 hour period.

### Pain management at end of life

When someone is dying any type of pain can be significant and overwhelming, it may often be necessary to make a number of medication changes towards the end of an individual's life.

A person's condition requires continual monitoring in order to enable a good level of pain/symptom control.

Evaluating the effectiveness of medications forms an important part of individualised care at the end of life.

Pain is thought to be one of the commonest symptoms at the end of life but dying people may suffer from many other symptoms.

## Medication

Drugs used to treat pain:

- Drugs used to treat pain are known as analgesics. Some analgesics work directly on pain (such as paracetamol for headache), while other medication is used for pain and has an indirect action (such as antidepressants).
- A group of drugs known as opioids are the largest group of direct analgesics used in palliative care e.g. weak opioids are drugs such as codeine and strong opioids are drugs such as morphine.

## Side effects of analgesics (Pain relieving drugs)

Strong analgesics have three common side effects:

- Drowsiness – usually wears off a few days after commencing medication.
- Sickness – anti sickness medicines help and this usually settles gradually over a few days.
- Constipation – is a common side effect and everyone taking a strong analgesic needs to take regular laxative.

Doctors, nurses and pharmacists can advise on treatments for side effects.

There is a very useful tool available to download from the website [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk). This is called the DISDAT Assessment tool. A range of additional resources and reference materials are also available using this link.

## Concerns about Morphine

Patients/families/carers often have questions about morphine:

- Is it addictive? – addiction is not seen in patients taking morphine for pain.
- Will it wear off? – pain relief due to morphine does not usually wear off.
- What about side effects? – many side effects of morphine do wear off. Constipation is an exception and is treated with a regular laxative.
- Does morphine kill you (or do you die sooner)? – used correctly, morphine does not kill patients.
- Can you be allergic to morphine/can everyone tolerate morphine? – most people can tolerate morphine, but alternatives to morphine are widely available.

## Communication problems in people with Dementia or Learning Disability

Remember some people with communication difficulties may not be able to tell us they have pain or distress, this makes it important for us to observe an individual's behaviour, as changes in usual behaviours may indicate distress which can be physical, emotional or psychological.

We should consult with other people who know the person and may be able to tell us about patterns of behaviour when the individual is content and how they are affected by symptoms.

Some examples of this are pushing food away if they feel sick, becoming withdrawn if they are in pain and becoming disruptive if they are distressed. Every person is different.



# 5

## Information about common symptoms which may occur at end of life

### Breathlessness

At the end of life some people may feel breathless; this can be very frightening and unsettling not only for the person themselves but also for the carers looking after them. These feelings of anxiety can actually then make the breathlessness worse so people caring for the person need to be aware of this.

#### What can help?

- Some physical positions are better than others for people that are breathless. E.g. sitting forwards supported on a table may be better than lying back for some people.
- Helping the person to lower and relax the shoulders will increase the space available for the lungs to expand. This is best done by sitting to one side or behind the person and gently massaging their shoulders down
- Loose fitting clothing is preferable.

The environment must be considered, it should be:

- calm
- cool – a fan is good
- have a good circulation of air – not stuffy
- consider things like smoke, noise, other people who may “bother” the person, increasing his/her anxiety.

### Drug therapy

#### Remember

Extra care housing staff cannot advise on medication. The following section is included for information purposes and reference only.

There are medicines that can be very useful:

- Oxygen can be supplied into homes.
- Relaxation therapy can help if breathlessness is made worse by anxiety by helping to prevent hyperventilation and giving the person and the carer strategies to use calming music, relaxation tapes or any other means that the person can understand/enjoy (slight change of emphasis).

## Tiredness and lack of energy

When people become more ill they gradually become less able to do the things they previously did and have less energy.

### There are 6 main principles in managing this:

- 1 take frequent rests
- 2 prioritise activities
- 3 plan ahead
- 4 organises tools, materials and work areas – store things in easy reach
- 5 adopt a good posture
- 6 lead a healthy lifestyle.

These are all aspects that care and support staff can help with by prompting and offering reminders, encouragement and suggestions.



### What you can do

When people say they are tired it is important to encourage them to:

- Pace themselves
- Carry out activities etc at times of the day when the person's energy levels are at their best
- Save energy for the things that matter to them and that they enjoy
- Just do as much as they feel like – more harm can be caused by doing too much
- Rest and relax more – that can actually mean doing nothing
- Understand that they may have less concentration
- Understand that they may not be able to take part fully in what is going on
- Have their favourite things within reach to prevent wasting energy
- Rest on a chair or stool when doing things
- Avoid twisting, stooping or bending
- Carry out activities in a relaxed and efficient way to minimise stress on the body
- Avoid heavy meals as this affects people's energy levels
- Remember that medical causes such as poor thyroid function, poor nutrition, depression, cancer and chronic infection can cause tiredness and lack of energy.

If you suspect a medical cause ask for a medical assessment.

## Constipation

People who do not move around as much and are not eating and drinking as usual may get constipated. Many medicines taken during advanced illness also cause constipation as a side effect; this applies especially to pain relieving drugs. This symptom can be a major problem for people at the end of life and is often not identified until the person complains of pain/discomfort; this can cause much anguish and frustration for patients and their carers.

### What can happen if someone is constipated?

- vomiting
- tummy discomfort, bloating and/or pain
- anxiety
- people “cannot be bothered,” become lethargic
- colic – griping rhythmical pain in the tummy, that comes and goes every few minutes
- exhaustion
- confusion – toxins escape into the blood stream
- what looks like diarrhoea – this is fluid content from the bowel that “overflows” past the solid bulk of faeces and can produce faecal incontinence.

### What can be done?

- Laxatives act in different ways and they may be prescribed or recommended by doctors:
  - they can stimulate the bowel to work such as senna or
  - they can increase the bulk such as bran.

- they can soften the faeces such as docusate.
- Drinks such as prune juice can be useful but this may cause colic in some patients.
- Occasionally, an individual may require a suppository or an enema, however these are always given under professional guidance and would not be administered by care staff.
- Abdominal massage – specialist advice would need to be sought from GP.

### What you can do

- encourage people to drink more fluid
- suggest that high fibre foods are added to the diet, such as fruit and vegetables if they are able to eat them.

## Urinary Problems

Many people experience a range of problems with their bladder function. Immobility and lack of fluids can lead to very concentrated urine, infection and in some cases kidney stones.

Delay in beginning to pass urine is known as hesitancy, some people find it helpful to see running water e.g. a tap turned on to help them.

Some people have difficulty in passing urine and this can be very painful and distressing. This is often referred to as urinary retention.

## Important

You need to seek medical advice if this happens to someone you are caring for. A doctor or nurse can assess the cause of the problem and in some cases will insert a tube (catheter) into the bladder to let the urine out. Some people require to have a catheter in place for a long period of time.

Catheter Care is required to prevent infection or trauma. The catheter bag should be positioned below the level of the bladder. Care should be taken to prevent trauma or pulling of the catheter tube as it is held in place by a balloon.

You should notify the healthcare team if you note any cloudiness, bleeding or strong odour or if there is no urine being passed or the urine is bypassing the catheter and leaking out of the bladder.

Urine Infection: Many people develop recurring infections. Good toilet hygiene e.g. wiping front to back can help this. Urine infections can cause confusion, pain, frequency, and in some cases incontinence, or other behaviour change.

### Measures to help:

Frequent drinks, Cranberry Juice, hygiene.

## Loss of appetite

As illness progresses some people may lose their appetite and lose weight. This may be because of the disease or the psychological state of the person, such as fear of vomiting, depression, anxiety or an aversion to the quantity of food given to them.

**As people become more ill their metabolism slows down. The body cannot digest food as well therefore it is very important not to insist that people eat.**

It is important for carers to understand that at the end of life people do not have the same nutritional needs, food cannot “build up their strength” and in fact this may be one of the few aspects of life that the person can retain some control over.

## What you can do to boost appetite

Below is a list of some ideas that may help and techniques to try:

- offer little and often
- offer “tasty tit bits”
- have snacks available to “nibble on”
- have enriched food
- have drinks that are food supplements (these have to be prescribed by a doctor or dietician)
- encourage people to eat slowly – they are more in control
- some people enjoy a small glass of alcohol before a meal as this can increase appetite
- encourage eating for pleasure rather than for survival.

## And what you shouldn't do

- don't “nag” about mealtimes and eating
- don't insist people should eat in the restaurant even if they have done so previously – they may prefer not to eat in company.
- don't make people “finish” their meal.

Remember that there are many physical causes of loss of appetite such as nausea, cancer, pain, anxiety, depression, infection, peptic ulcers and oral problems. These need to be treated and managed.

## Feeling sick and vomiting

This can be due to the illness itself or the medication that someone is taking. People who are ill often say that this symptom of feeling sick is more distressing than actually vomiting, or than some types of pain, therefore it is very important that the people caring for these individuals know this.

### What can cause nausea and vomiting?

- many medications can cause nausea and/or vomiting such as anti-inflammatory drugs, e.g. ibuprofen, aspirin and diclofenac, antibiotics and a group of drugs known as strong opioids, e.g. morphine
- some medical problems can also cause vomiting e.g:
  - bowel obstruction, this could be constipation
  - inflammation of ulcers
  - high levels of calcium
  - problems with the inner ear.

### What can be done by health professionals?

- The doctor will find out the cause of the sickness, this may need further tests or be obvious by looking at side effects of medication.
- The doctor can prescribe anti-sickness medicines. These can be taken as tablets given as suppositories or given in a

special pump. They should be taken regularly to prevent the sickness returning.

## Things you can do to help

There are some useful tips worth trying such as encouraging the person to:

- eat dry foods such as crackers
- have ginger (can be drunk as tea or ginger beer)
- have warm or cold food which does not smell as strongly as hot
- don't prepare or cook food within eyesight or "smell distance"
- avoid strong smells in the environment including perfumes etc
- sip fizzy drinks
- eat little and often.

## Mouth problems

People can sometimes develop very sore mouths at the end of life; this can be a very distressing symptom and can be a side effect of some medicines.

Palliative treatments such as chemotherapy and radiotherapy can also cause sore mouths.

### What else can cause a sore mouth?

- poor oral hygiene – by carers
- no longer able to clean teeth
- reduced food and drink intake
- dehydration
- oral thrush and other mouth infections
- poor fitting dentures

- mouth breathing
- oxygen therapy.

### What can be done?

Doctors/health professionals to:

- review all medicines
- treat any infection such as thrush.

### What you can do

- Give regular mouth care especially after meals.
- Use pineapple juice or soda water to clean the mouth (crushed pineapple if the person can chew/swallow). Pineapple juice is less harsh and abrasive than other citrus fruit juices and stimulates saliva production. This can be mixed with a thickening agent if a person cannot swallow effectively.
- Use gauze or sponge swabs (caution is necessary as some people may bite at the swab).
- Vaseline or similar for lips (caution is necessary if a person is receiving oxygen, as Vaseline is flammable).
- Consider use of anti fungal/anti bacterial mouthwash.
- Check the fit of dentures (at the end of life gums can shrink) and clean well and regularly.

### Encourage the person:

- to take frequent sips of water
- to use fruity or fizzy sweets
- to suck pineapple chunks or kiwi fruit.

## Eating and drinking

As people get older their eating and drinking habits change and this is especially the case for people with life limiting, life threatening illnesses and those reaching the later stages of their life.

Some things that you can ask yourself are:

Has the problem:

- Come on suddenly?
- Come on gradually?

Are there reasons why the person does not want to eat?

- Is there a problem with their mouth, gums or teeth?
- Are they in pain?
- Is the person constipated?
- Have they got an infection?
- Do they feel sick?
- Are the tablets they are taking affecting their appetite?
- Is the person breathless?
- Is the person depressed?
- Is the person frightened?
- Is the person easily tired or fatigued?

All of these signs are treatable to some extent and therefore further exploration may be necessary.

### What is the food like?

- Is the portion too large?
- Does the food look appetising?
- Does the food smell nice?
- Is the consistency right?
- A little thought can make a big difference when trying to tempt people to eat.

### What is the environment like?

- Is it noisy?
- Is it crowded?
- Is the person in a comfortable sitting position?
- Is the person being offered the right amount of support?
- Would special/different plates, cups, or cutlery help?

The environment can have a big effect on how we eat and drink and problems, when discovered, are usually easily overcome. You may find that people who have enjoyed eating in the restaurant prefer to take meals in their own apartment.

### Does eating and drinking appear difficult for the person?

- Do they take a long time to finish a meal?
- Do they cough or splutter throughout or just after having a meal or drink?
- Does food or drinks dribble out of their mouth?
- Do they store foodstuff in their mouth for a long time?
- What if there are communication difficulties? (Important).

### Things that can help

- eliminate and treat causes of reduced appetite
- keep portions small, and try snacks rather than large meals
- try varying taste, consistency and temperature of food
- be creative with food to ensure maximum benefit from minimal input
- food supplements can be helpful if food intake is reduced
- keep the person's mouth clean, and moist
- avoid unpleasant smells, cooking odours and avoid strong perfumes
- give the person privacy if embarrassed about eating/drinking
- give the person the correct amount of support at mealtimes
- change the equipment/utensils/seating used
- if in doubt ask for a swallowing assessment.



# 6

## Mobility Issues

As people get older their ability to move around can change, they can get slower, be not so flexible and can fall over more often with no apparent cause. This is especially the case for people with life limiting, life threatening illnesses and those reaching the later stages of their life.

### Some things that you can ask yourself are

Has the problem:

- Come on suddenly?
- Come on gradually?

### Are there reasons why the person does not want to move about?

- Has the person suffered any recent trauma?
- Has the person got any sensory problems, e.g. visual problems?
- Could the person have arthritis or any other physical condition?
- Is there a problem with their joints or muscles?

- Are they in pain?
- Is the person constipated?
- Have they got an infection?
- Are the tablets they are taking affecting their balance or movement?
- Is the person breathless when moving?
- Is the person depressed?
- Is the person frightened?
- Is the person confused?
- Is the person easily tired or fatigued?

All of these signs are treatable to some extent and therefore further assessment and/or investigation may be necessary.

### What is the environment like?

- Is it noisy?
- Is it crowded?
- Is the person in suitable footwear?
- Is the chair at the best height for the person to get out of?
- Is the person being offered the right amount of support?
- would a walking aid help?



- Is the flooring appropriate?
- Are the problems present in a specific activity, e.g. bathing, stairs etc?

### Does moving around appear difficult for the person?

- Do they take a long time to walk a short distance?
- Do they have an obvious limp or other mannerisms when walking? Do they stagger or lose their balance often?
- Do they appear to have problems when starting or stopping walking when asked to?
- Do they step over or walk around unseen objects on the floor?
- Is there a lot of hesitation at changes in floor surface or stairs?
- Do they bump into doors walls etc?
- Do they seem unable to sit straight?

These signs could all indicate problems that would need further assessment from other professionals.

#### Important

At the end of life there are no right and wrong decisions about moving about, sitting up in a chair or being in bed all day. At this stage what is best is what provides the person concerned with most comfort and pleasure. What the person and people close to them feel is best for them is everyone's most useful guide.

#### Things you can do to help

- eliminate and treat reversible causes of mobility problems
- use good signposts to aid moving from one place to another
- look out for and remove trip hazards
- offer the correct level of support
- encourage activity little and often
- use aids to ease daily living skills e.g. getting in and out the bath
- have good footwear
- consider specialist equipment
- adaptation of the environment
- consider massage and other comfort measures.

#### And remember

Physical contact can be a powerful way of communicating to someone how much you care and how you will support them especially when they are faced with uncertainty, fear, or distress whether physical, psychological or emotional.

# 7

## Religion, culture and spiritual needs

The United Kingdom is a richly diverse multi cultural society and due to that we will come across people who have been brought up with different religious/cultural backgrounds. As carers and housing staff we must acknowledge this, especially at the end of life, as at this time there can be many rituals connected with it.

All people's lived experiences are different and it is important to acknowledge this in how we offer support to them. This is particularly important when working with people with dementia and communication difficulties. We need to ensure our approach is truly person-centred. Refer to information collected on file such as an Advance Care Plan. Also the information given when people first move in. It can also be useful to talk to family members to build up a picture of who people are and what they value.

**Spirituality** is very difficult to define as it can mean different things to different people. However it has been said that spirituality is that aspect or essence of a person's soul that gives him/her power and energy. In other words "it's what makes us

tick". Spirituality is to do with relationships with something or someone and it is important to support people with a learning disability to make connections with what or whom gives them greatest hope, purpose and comfort.

**Religion** can be described as any specific system of belief, worship or conduct often involving set rituals and a philosophy and a way of perceiving the world. For some people praying and a belief in a good life after death can be a source of reassurance and comfort and if the person you support has been brought up with this belief it is important to help them achieve it.

**Culture** is not so much as where we came from geographically, but more about our lived experience; the way we were brought up, the practices and traditions that have been passed on from generation to generation. This can be customs and rituals, religious or otherwise. We must try and support the person to maintain these.

### Important

In reality spirituality and religion can get all mixed up. However the main thing is to respond to people as individuals. We must also remember that just because people may not follow any particular religion it does not necessarily mean that spirituality is not important to them.

### Things to consider:

- Diet – cultural and/or religious limitations of diet and food preferences must be considered. e.g. vegetarian or kosher food.
- Names – differences in languages can hinder communication so we need to be mindful as to how people wish to be addressed.
- Washing and toileting – there can be many differences in practice dependent on cultural/ethnic background. It is important to check.
- Modesty – this is an area that needs to be treated with the greatest respect at all times. For example, generally Muslim women prefer not to be examined or surrounded by male members of staff.
- Attitudes towards medical staff and illness – generally people willingly accept the authority of the professional in medicine. However, people from different faiths can have different attitudes.
- Death – there are many rituals associated with death in all cultures and religions and these must be respected if the person you are caring for has known religious beliefs or are from a different ethnic background from yourself. You must seek advice from the appropriate people. Refer to your organisation's diversity policy or you may want to speak to your equality and diversity officer if you require further specific guidance.

### What you can do

It is in the “being” not “doing” that often counts at this time of life. Just being there, sitting quiet with someone can often give much comfort.

Don't try and solve problems for people, we are naturally 'fix it' people but at the end of life it is often better to allow things to happen.

Be aware of the spiritual dimension, we all have 3 dimensions, body mind and spirit.

If the people you are caring for are having difficulties in expressing themselves try using practical methods such as music, photographs, drawing and painting or aromatherapy.

Find out if the person you are caring for has expressed any previous wish or desire for particular things to happen/ take place.

Has the person a different ethnic background from you? If so has he/she got any family members who can advise you or is there a local group nearby?

Don't assume that if someone is recorded as belonging to a particular faith that they practice it! After all many of the general population are recorded as “Church of England” but may not have been to church or practiced any of the associated rituals for years.

It is important not to impose your own belief system onto the person you are caring for or to allow the family to do so if the person does not want to participate.

**Remember, if in any doubt seek advice.**

# 8

## Last days and hours

### What might happen?

As the end of life approaches the person, family and carers all have to make adjustments. Some small adjustments may have already been made over weeks or months, but as death approaches the reality of the situation makes things more difficult for some people.

It is normal for carers and professionals to be affected by the death of the people that they are caring for. It can be a frightening time if a carer has not experienced it before, they can be unsure what to do, how to act or will they “get things right”. Most deaths in these circumstances are expected and therefore can be planned to some extent, which can help to alleviate some, if not most of these fears.

However, in some instances, although the person has a disease which is life limiting/ life threatening, they may die unexpectedly and their death may not have been anticipated i.e. deterioration may not have reached the day by day stage. When a person dies in these circumstances it may cause more emotional upset to their families/carers than if their death had

been anticipated as imminent. This is often due to the suddenness of the death and missed opportunities to say “goodbye” or have people significant to the person present at the death.

Although dying in this way is unexpected it is not the same as a “sudden death” where the person has previously been fit and well with no advanced disease diagnosis, therefore it is very unlikely the responsible doctor will ask for a post mortem or any of the other procedures associated with a “sudden death” if he/she has seen the patient within the last fourteen days, (for a doctor to issue a death certificate this is a requirement of English law).

### What happens to the person?

- For most people with advanced illness there is a gentle “winding down” of the body’s systems, this can be described by the general principle of deterioration in the person’s condition happening:
  - month by month
  - day by day
  - hour by hour.
- As they approach the end of life, their circulation slows so that their fingers, nose and toes feel cool and are a little bluish or mottled.

- Their breathing pattern may change and become slower or irregular.
- At the end there is a gentle absence of life rather than a sudden presence of death.
- Peaceful silence.

### What happens to others?

Everyone can respond differently

- some cry, others don't
- some talk, others are quiet
- some feel helpless and useless
- some feel awkward or an urge to "do something"
- everything is normal.

### Important – things that can help

- Don't panic or feel that you can't be upset.
- Someone will need to check that the patient has died and then inform the GP or District Nurse to come and certify the death.
- After the death ask those present (if any) if they want to stay a while.
- Contact any significant people or family not already there and notify them.
- Tell the other people who live with the person who has died, there is no right or wrong time for this.

- The doctor who saw the patient within the prior few days should write the death certificate.
- There is no requirement for nurses to clinically confirm that death has occurred, they only need to document the fact, the time it occurred and who was present.
- The death will need to be registered at local registrar's office in the sub district where the death has occurred.

### Things that may be helpful during the last hours and days:

- Have a list of telephone numbers of people you need to contact by the phone – this should include "out of hours" doctors.
- Have your usual GP write out an explanatory letter for staff to show "out of hours"/locum doctors when they call. This takes the pressure off the staff/family.
- Ensure that you have enough of the required medication at all times.
- Sit down and talk to others who are friends or live with the dying person so the end does not come as a shock.

# 9

## Care after death

### What to do when someone dies

Many people have had no experience of being there when someone dies and/or having to deal with the practical aspects that follow death. They can become extremely worried that they do not follow the correct procedures and this can be on top of having mixed emotions about the death of the individual. The death of someone close to you is a profound and significant event and everyone reacts differently: people can feel shocked, numb, upset, angry or in fact relieved that the person is now at peace.

There are some things that need to be done, however you do not have to do them immediately, don't feel rushed.

### Who to contact:

#### The relatives:

- If the person's next of kin is not aware of the death you will have to notify them – some relatives will have expressed a wish with regard to the time of informing them of the death e.g. some people may not wish to be informed during the night, other people may wish to be informed at any time of day or night.
- If there are no documented requests from the relatives they will have to be informed as soon after the death as possible.

#### The GP:

- You will need to inform the GP or out of hours doctor.
- They will come out and certify death. If this is outside normal working hours either the out of hours doctor will come or the GP will come at the earliest opportunity. In cases of expected deaths, if the district nurse has been involved in the care they can attend and verify the death.
- The GP has a legal requirement to inform the coroner if a post mortem is needed, however with an expected death this is usually unnecessary.

- The doctor will give you a certificate of death with a form called 'Notice to Informant' which tells you how to register the death.

### The Funeral Director:

- Once they have the death certificate the next of kin should contact a funeral director (they provide 24 hour service).
- They can then take the body to their Funeral Home (They can help you look after the body at home if you want that, this may apply more to some specific religions/cultures than others).
- They will ask about funeral arrangements.
- It is helpful to know any expressed wish of the deceased person, e.g. did they want to be buried or cremated? This is sometimes on admission documentation.
- You need to be aware of any cultural or religious beliefs so they can be acted upon.



### Registering the death:

- This needs to be done within 5 days.
- If there are no known relatives check the information file in the office which details tenant records.
- If there are relatives contact them.
- The registrar will issue a certificate of burial or cremation (also known as a green form).
- The family will give this to the funeral director.
- They will also give them a certificate of registration of death form (BD8). This is required for social security purposes.

### Other pertinent people:

- You will have to inform your line manager/ locality manager/point of contact.
- Friends of the person who has died. It is important to recognise that other tenants may be affected by the death of a tenant. It is really helpful to be honest with them and allow time to talk about the person.
- It can be useful to have an annual remembrance service or other appropriate event to remember tenants who have died.
- You could also speak to health professionals if you are concerned that some tenants are particularly affected by the death of a fellow tenant. Bereavement is difficult for everyone and affects people in different ways, but some people are particularly at risk of being adversely affected.

# Case Studies and Testimonies

**All of the examples in this section are drawn from actual situations in extra care housing and are written from the perspective of staff and relatives. However, names and specific details have been changed to protect the identity of individuals involved. Research evidence has shown that health professionals, hospital staff, relatives and residents often like to see practical examples or case studies about how people can be supported in extra care housing. It is also useful to highlight challenges and obstacles to delivering choice and supportive care.**

**These examples can also be used as training aids to stimulate discussion and think about practical solutions to issues arising. They are intended as a starting point. It may be useful to develop your own case studies arising from your own experience. When writing up any examples try to identify what worked well for people, what were the most difficult things, how did you feel and how did you respond.**

## **Mary**

Mary was a ninety six year old lady who has lived at Court A since it opened a couple of years ago. She began to become gradually more frail and she needed more help from the care staff for personal care. She eventually became bed bound and we could see she was dying. The GP asked her family if they felt she could go into hospital. Her daughter was adamant that she should remain in the court in her own flat, with care staff who she knew and had a good relationship with. This was Mary's preference. The GP reluctantly agreed and arranged for the District Nurse to Call.

The Court Manager contacted the social worker and arranged for authorisation for the Care Package to be increased. The nurses arranged a special mattress to relieve pressure and some moving and handling equipment. They advised the staff about positioning and pressure area care and arranged to come in twice daily. They left contact numbers to get in touch over 24 hours for advice or to visit. They also left mouth care packs and swabs to clean her mouth.

The family were sitting with Mary but Court A staff delivered all her care and every time they passed the flat they would call in to check her comfort, position and pressure areas.



She was very settled and the staff even put some of her favourite perfume on a tissue under her pillow. The staff continued to talk reassuringly to Mary during all of their care tasks even though she was semi conscious. Mary died comfortably 3 days later with her daughter and the court manager at her bedside. The care staff at the court expressed how they felt privileged to provide her care right to the end of her life and it felt appropriate that she died in her own flat.

### Macmillan Nurses working with extra care housing

We have looked after many people in the court who have died from cancer. The local Macmillan Nurse arranges regular visits from district nurses to sort out medication and arrange equipment. We always feel that when the Macmillan nurse is involved, this helps people to remain in the court even when they reach the dying phase. She has conversations about what to do in situations and makes sure we understand how to get advice at night or over the weekend. She also lets the doctor know that the person wants to stay in the court.

In recent times she now completes an advance care plan and lets the staff know where this is kept. The court staff find this is really helpful if a doctor is called. It is also useful if relatives say they think their family member should go to a hospital or hospice. We think that everything falls into place when the Macmillan nurse is involved. We now have community Matrons who look after some of the tenants who have respiratory problems or cardiac conditions. They also do an advance care plan and leave advice with court staff how to help if a tenant gets anxious or breathless and who to contact.

### Sarah

Sarah was a 78 year old woman with dementia and a history of COPD (Airways disease). She was very breathless and used to be a heavy smoker. The Community Matron had just started to be involved to help manage her symptoms. Sarah was very popular with the other tenants and they all looked out for her. One weekend she had a fall in her flat and the staff called the doctor.

She was admitted to hospital where they found she had some sprains but no fracture. The hospital staff said she needed some rehabilitation before going home to improve her mobility. The court manager then got a call from the hospital to say she had developed a chest infection. After a week she visited Sarah in hospital and Sarah was asking when she could come back home to the court. The manager told her that everyone was looking forward to her coming back and Sarah was delighted.

Sarah's niece called into the room just as the court manager was leaving and said 'My aunt would never manage at home now, and we've got a meeting with the hospital social worker'. The court manager spoke to the ward staff and requested that she be contacted for their planning meeting for Sarah's discharge. She called the ward a week later and was told there would be no meeting as Sarah was going into a care home.

After two weeks Sarah's niece came to the court to collect her belongings, saying she had just moved into a care home, and was really confused just staying in her room all the time. Sarah developed another chest infection in the care home and was taken back to hospital where she died three weeks later.

The court manager felt very frustrated that Sarah was not given the opportunity to return to her own home and be cared for by staff who knew her well. After all, this was what Sarah wanted. The court manager arranged to visit the hospital social work team to inform them what care can be provided in extra care housing. She also tried to set up some meetings with the discharge planning teams at the hospital to identify a range of issues around hospital discharges and to request that court managers are informed about any plans for discharge.

### Care and support staff perspectives

"We try to support relatives as much as possible. When one of the tenants is poorly we offer family and friends the use of the relative's room to get some rest. It can be hard after a tenant has died."

"Our community matrons have started to draw up a plan about care wishes and preferences with all our tenants that they are involved with. This is very useful for all the staff to show to doctors if they are called out and want to take someone to hospital. It's really helpful and the medical staff take notice of it. They now look at ways of giving medication at home instead of sending people to hospital."

### Relative perspectives

"During my mum's last few days we were not only supported way beyond the court's brief but my mum was looked after with such sensitivity that it made her passing dignified and peaceful. My gratitude is obviously for my mum's care, but also I feel quite privileged to have been part of such a caring community and would love to think that standard of care could be available to all those who needed it." (Excerpt from a letter received by Housing 21).



# 11

## Sources of Education and Training

There are many different sources of education and training opportunities that may help you to feel more confident in caring for people at end of life. There are regular courses provided by local palliative care teams and hospices in many areas.

Many district nurses and community matrons are available to discuss how to support specific residents they are caring for. The community matrons will explain why it is appropriate to put plans in place to manage some situations which may happen. This can help avoid crisis situations and help reduce panic for residents, care staff and family members.

It is also useful to look at case studies of people at end of life care to demonstrate how the care was managed. Some are included in the previous section of this

pack, all from Housing 21 courts, but you may wish to write up your own from professional experience. Think about the challenges, how these were overcome and the learning points, and include them as additional resources in this pack.

There are a range of national workforce initiatives to improve the skills of people working in health and social care. In conjunction with Skills for Health and Skills for Care there has been work undertaken to produce principles and competencies for workers who look after people at the end of their life. There are also communications skills training pilots and e-learning materials. For further information look on the workforce page of [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).

For Housing 21 and other specialist housing providers – we would ask local area managers (care service managers, possibly court managers and/or the corporate learning and development team) to research sources of training and support and include this information in the resource pack folder.

# Useful Information

Some useful additional resources are included here. Staff may wish to add to this over time.

## A quick overview of extra care and sheltered housing

This factsheet is also available to download from the End of Life Care Programme website. It may be useful to print out copies and give them to health professionals like GP surgeries, community matrons, district nurses and other statutory and voluntary sector organisations you work with so that they have a clear understanding about what is offered in extra care (and sheltered housing).

## Flow chart for supportive care

This was developed as part of Housing 21's service improvement work in one of the case study sites and can be adapted for wider application.

The following websites are all sources of useful information and support materials:

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

<http://networks.csip.org.uk/independentLivingChoices/>

[www.housing21.co.uk](http://www.housing21.co.uk)

## A quick overview of sheltered and extra care housing

This brief introduction outlines the key features of sheltered and extra care housing and summarises how both types of retirement housing contribute to community care and health goals; specifically end of life care.

## Background and policy context

Many people are familiar with sheltered housing for older people which has existed in various forms for more than forty years. Extra care is a more recent development and offers specially designed housing with the addition of 24 hour on-site care.

In July 2008 the Government published its national End of Life Care strategy which provides a framework to promote high quality care for adults approaching the end of their lives with a vision to “enable more people to die with dignity in a place of their choosing”. The strategy recognises the value of extra care and sheltered housing and draws attention to the needs of extra care residents at the end of their lives.

Sheltered and extra care housing are important community resources in supporting an ageing population.

The Community Care Act of 1990 laid down the aims of providing care within older people's homes rather than institutional settings. In its national housing strategy for an ageing society, Lifetime Homes, Lifetime Neighbourhoods (HMSO, 2008) the Government sets out a clear role and vision for the future for specialist housing and emphasises the important links between housing, health and social care.

## Extra Care Housing

### What is it?

- Schemes or “courts” typically contain 30 to 60 self-contained apartments with full kitchen and bathroom facilities designed to mobility and wheelchair access standards.
- Offers the full legal rights of occupation associated with being a tenant or home-owner in combination with access to 24 hour on-site care which is delivered flexibly according to a person's changing needs.
- Schemes offer a diverse range of community facilities; communal lounges, hairdressing salons, shops, laundry facilities, consulting rooms and restaurants. These facilities are available to both residents and older people in the wider community.
- There are now over 1,000 extra care housing schemes across England. Many more are being built, mainly by housing associations and private developers.
- Extra care can be for rent, outright sale or part ownership. There are a range of different sizes of scheme and “retirement village” type developments containing over 300 dwellings are becoming more common.

### And what it isn't!

- An ‘upmarket care home’. This is a common misconception of and can create confusion about the way care is delivered. In extra care housing, care is delivered as part of a care plan at set times agreed with the resident. Residents have their own front door, so carers can't just pop in anytime unlike in a residential care home.

### Who is extra care housing for?

- Designed for older people who have some care and support needs. People often move in because of a health problem or following a personal crisis.
- Most (but not all) people living in extra care housing have a care package of at least four hours of personal care per week. Care is generally assessed and paid for by local social services.
- Extra care housing can enable older people to recover from a stay in hospital and as a base for rehabilitative and intermediate care. This works well if hospital staff actively involve extra care managers in discharge planning.
- Some schemes include clusters of flats specifically for people with dementia.
- A diverse range of activities are provided by scheme staff, local statutory and voluntary organisations. These are available to residents and older people in the local community.

## Care and support

- Care teams are based on-site as are staff responsible for building management and co-ordination of support services (“Court Managers” or “Estate Managers”).
- Community health resources: Many extra care housing schemes have on-site falls rehabilitation clinics, GP surgeries, visiting chiropodists, district nurses, opticians and Community Mental Health Teams (CMHT).

## Sheltered Housing

### What is it?

- Schemes or “courts” comprise 30 to 40 flats and/or bungalows with an emergency alarm call service and some communal facilities such as a resident lounge and laundry.
- Individual flats or bungalows are designed to be easy to manage.
- On-site support is often provided by a scheme manager (“warden”).
- Offers older people privacy, independence and peace of mind with the added benefit of a social community. It can prevent dependency and reduce social isolation and depression.
- Provided in a range of tenures; rental, part ownership or outright sale. Most rented sheltered housing has been developed by local authorities or housing associations.

### Who is it for?

- Originally intended for active people over 55, but over time more older or frailer people are living in sheltered housing.
- The likelihood of living in sheltered housing increases with age. 4% of people aged 65–69 increasing to 19% of those aged 85 or over.
- Increasing numbers of older people living in sheltered housing have sensory impairments, mobility problems or mental health issues.
- It is a community resource and often the facilities and activities provided are used by older people in the wider locality. Schemes usually have established links to other statutory and voluntary service providers for older people.

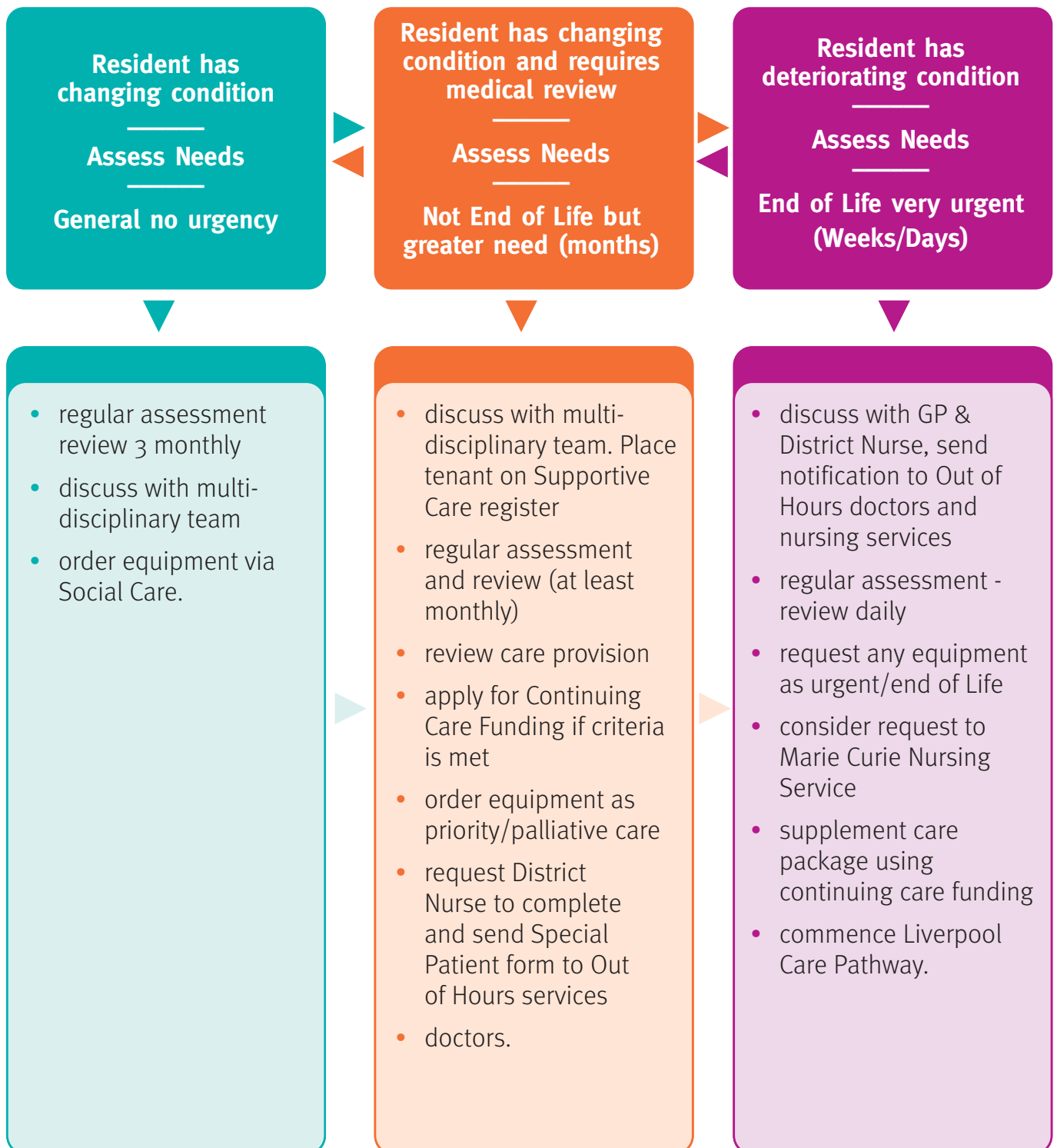
### Care and support

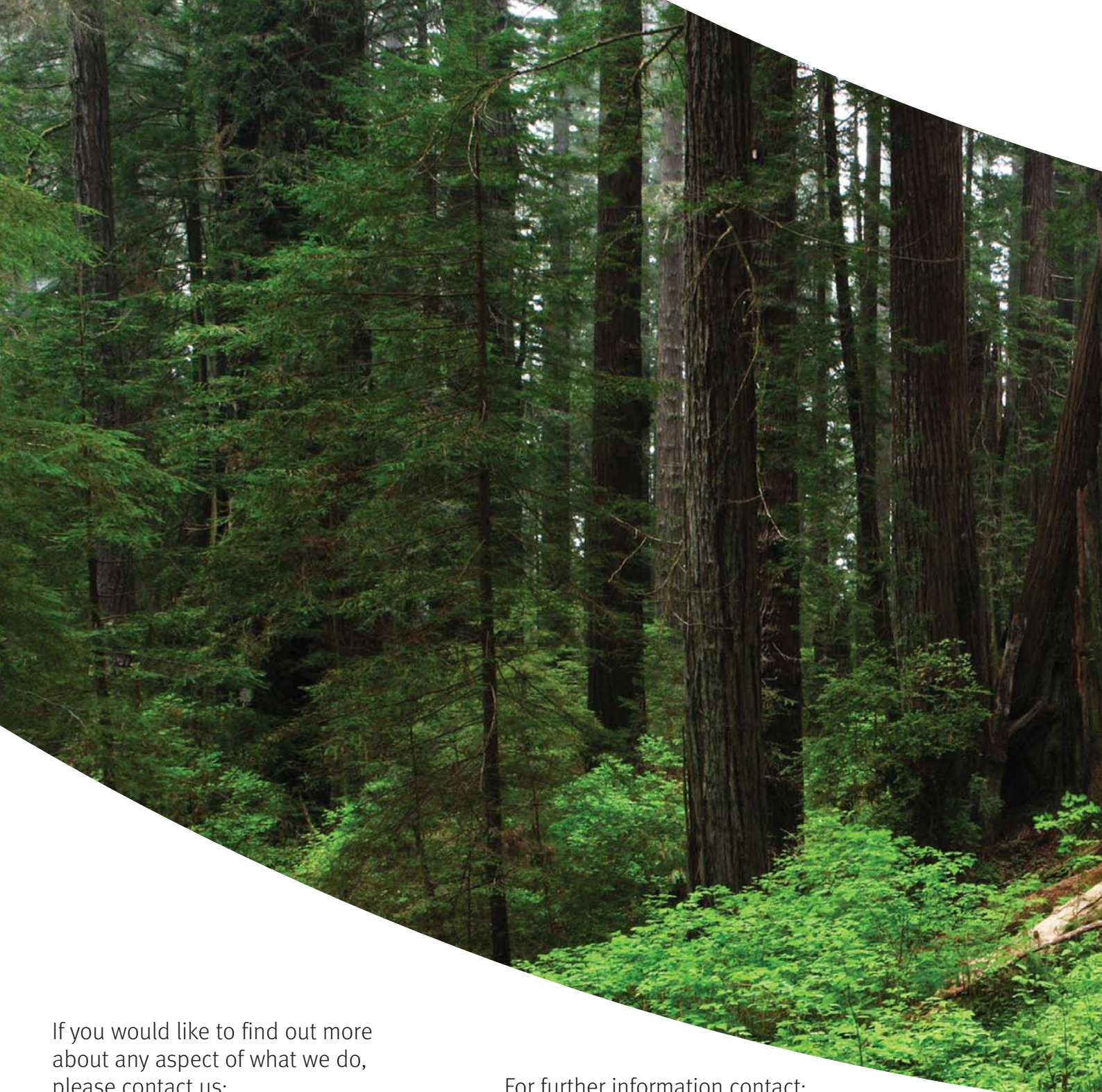
- Care is not usually provided but residents are entitled to be assessed for care and support by their local authority. If eligible they can obtain home-care services from social services.

For more information on sheltered and extra care housing – see <http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing> or [www.housing21.co.uk](http://www.housing21.co.uk)

# Extra Care Housing

## Flow Chart for Supportive Care





If you would like to find out more about any aspect of what we do, please contact us:

Housing 21  
The Triangle, Baring Road  
Beaconsfield, Bucks HP9 2NA

Tel: 0370 192 4000

Fax: 0370 192 4001

Email: [enquiries@housing21.co.uk](mailto:enquiries@housing21.co.uk)

[www.housing21.co.uk](http://www.housing21.co.uk)

For further information contact:

End of Life Care Programme  
3rd Floor, St John's House  
East Street, Leicester LE1 6NB

Tel: 0116 222 5103

Fax: 0116 222 5101

Email: [information@eolc.nhs.uk](mailto:information@eolc.nhs.uk)

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

If you need this information in a different format such as large print, braille or another language, please contact us.

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