



End of Life Care

A Resource Pack for
those caring for or
supporting people with
a learning disability at
the end of life

What can we do?

A guide to offering care and support to people with a learning disability at the end of life

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Introduction

This guide is designed for anyone who is caring for or giving support to someone with a learning disability who is terminally ill.

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.

Providing effective, high-quality care for someone during the end of their life is a highly skilled role. Without support and information, staff and carers can find the experience overwhelming, trying to react to changing needs during a period of grief. The ability of staff and carers to cope can be increased by having information available that will help them do the things that need to be done.

This guide has been developed to try and help anyone trying to support a person with a learning disability during the end of their life, and after they have died. The guide contains a series of easily accessible, straightforward, practical and realistic sections to be used by anyone supporting someone with a learning disability.

How to use the guide

This guide is arranged in four main sections:

Section 1 - maintaining health

Section 2 - living with dying

Section 3 - challenges and solutions

Section 4 - useful information

Each of these sections is designed to be used alone or together with other parts of the guide.

People who can help and where they can be contacted:

Contact information for key people in _____'s life

Family members _____

Friends _____

Please refer to the local, regional and national list of resources/contacts located at the end of section four to help you identify the contact for your area. For specific professionals who can help, contacts are listed at the end of each profile relating to individual roles.

Advocate

My local contact is _____

Bereavement Service

My local contact is _____

Care Manager

My local contact is _____

Carers association

My local contact is _____

Catering staff

My local contact is _____

Citizens Advice

My local contact is _____

Clergy

My local contact is _____

Community Nurse

My local contact is _____

Complementary therapist

My local contact is _____

Consultant

My local contact is _____

Counsellor

My local contact is _____

Commission for Social Care Inspection CSCI

My local contact is _____

Dentist

My local contact is _____

Dietician

My local contact is _____

District nurse

My local contact is _____

GP

My local contact is _____

Hospice services

My local contact is _____

Independent Mental Capacity Advocate (IMCA)

My local contact is _____

**Learning Disabilities liaison group/Nurse
working with mainstream services**

My local contact is _____

Line manager

My local contact is _____

Macmillan Nurse

My local contact is _____

Marie Curie Nurse

My local contact is _____

Occupational Therapist

My local contact is _____

Palliative Care Consultant

My local contact is _____

Pharmacist

My local contact is _____

Physiotherapist

My local contact is _____

Psychiatrist

My local contact is _____

Social worker

My local contact is _____

Speech and Language Therapist

My local contact is _____

Undertaker

My local contact is _____



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section 1 - maintaining health

Pain and medication in end of life care

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Pain and medication in end of life care

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. For symptom control to be effective the dying person needs to have person centered care in order that their symptoms can be accurately assessed, monitored and appropriate treatment provided.

How can medicines be given?

Medication can be administered via several routes; pain relieving drugs can be given as:

- Tablets.
- Liquids.
- Patches applied to the skin.
- Injections.
- Medicines for pain 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.

Pain relieving medicine for each 24-hour period is made up by the doctor or nurse and given via the syringe driver. This enables the individual to receive a continuous dose of the medication; other medicines, for example drugs to treat nausea/vomiting can also be given via the syringe driver.

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 others have an indirect action (such as gabapentin).
- 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.
- If an individual is thought to be in the last hours / days of their lives, a decision may be made to use an end of life care tool known as the Liverpool Care of the Dying Pathway. If the pathway is in place the individual will be prescribed a combination of drugs to manage pain and other symptoms in end of life care – it is not always necessary for every dying person to receive these drugs but having them prescribed and available in the patient's home means there is no delay in giving the appropriate medication should the patient need it.

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 pharmacist can advise on treatments for side effects.

Patients/families/carers often have concerns 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 every one tolerate morphine? – most people can tolerate morphine, but alternatives to morphine are widely available.

Principles of using analgesics:

Doctors follow three well known principles when prescribing analgesics:

- **By the clock** – giving analgesics regularly enables continuous pain relief.
- **By the ladder** – low doses of analgesics are gradually increased then changed to stronger analgesics; this allows the dose of analgesia to be adjusted to meet the needs of each individual.
- **By the mouth** – where possible individuals usually prefer to take analgesics by mouth rather than by injection.

Actions, causes and characteristics of pain:

- Eating – sore mouth, gullet or stomach.
- Pain on movement – bone fracture.
- Taking a deep breath – Pleurisy, infection, tumour.
- Pain that comes and goes every few minutes – colic.
- Pain related to elimination (urine/faecal) - infection, urine retention, diarrhoea, constipation.
- Pain present at rest or in usual comfortable position – eg fear, anxiety, depression.
- Pain with vomiting – consider causes of nausea/vomiting.

Remember some people with learning disabilities may not be able to tell us they have pain, 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.

The Disability Distress Assessment Tool (DisDAT) enables carers to document these signs and behaviours and is part of a process that increases awareness of distress in clients with severe communication difficulties, as well as enabling them to identify its cause.

See www.mencap.org.uk for the latest version of DisDAT.

Common symptoms at the 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:
 - There are medicines that can be very useful such as antibiotics.
 - Opioids are also effective in reducing breathlessness.
 - Steroids can help in some cases.
 - Nebulisers can be very effective.
 - Low doses of appropriate drugs such as valium can help with relaxation.
 - 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. Use calming music, relaxation tapes or any other means that the person can understand enjoy and that works.
- Complementary therapies may be considered – this will require advice from an appropriate professional such as an aromatherapist.

Common symptoms at the end of life

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:

- Take frequent rests.
- Prioritise activities.
- Plan ahead.
- Organises tools, materials and work areas – store things in easy reach.
- Adopt a good posture.
- Lead a healthy lifestyle.

Therefore, when people complain of being 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 peoples 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.

Physiotherapists and Occupational Therapists can advise about aids and adaptations that can make most of the person's strength and energy, as well as organising some specialist equipment.

If people are not moving around as much care should be taken that they do not develop sore areas such as on their heels and bottom. Again advice can be sought from district nurses, physiotherapists, occupational therapists or other specialist nurses such as Macmillan nurses.

Adapted with permission from "Some helpful tips on Fatigue Management" St. Oswald's Hospice.

Common symptoms at the end of life

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 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:
 - 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.
- Encourage people to drink more fluid.
- Add high fibre foods to the diet, such as fruit and vegetables if they are able to eat them.
- 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.
- Abdominal massage – specialist advice would need to be sought.

Common symptoms at the end of life

Loss of appetite

As the 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.

Many carers feel that food is a very important part of life and worry when food is refused believing that the individual is “starving to death” and that they are being neglectful by not getting their person to 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 can be done to boost appetite?

- Offer little and often.
- Offer “tasty tit bits”.
- Have snacks available to “nibble on”.
- Have enriched foods.
- 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.
- Don’t “nag” about mealtimes and eating.
- Don’t make people “finish” their meal.
- Some patients with poor appetite due to cancer can respond to a low dose of steroids.
- Many people have stomachs that empty slowly and this can be worsened by advanced illness. It can cause people to feel full up quickly or all of the time, as well as indigestion, hiccups and sometimes vomiting large amounts. This does respond to drugs that speed up the emptying of the stomach. A nurse or a doctor could advise you about this.

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.

Common symptoms at the end of life

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?

- 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.
- 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.

Common symptoms at the end of life

Mouth problems

People can sometimes develop very sore mouths at the end of life; this can be a very distressing symptom for some people and may require treatment interventions and close monitoring. This symptom may be caused by the side effects of some medicines (dry mouth can be a common side effect).

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?

- Review all medicines.
- Treat any infection such as thrush.
- Give regular mouth care especially after meals.
 - Use pineapple juice to clean (crushed pineapple if the person can chew/swallow effectively / thickened with 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.
- Frequent sips of water.
- Use artificial saliva if prescribed and if the individual can tolerate / likes it.

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.

As activity levels diminish it is normal to eat and drink less but it can be difficult for carers to decide how much food and drink is appropriate or if there are any specific reasons why someone is having difficulties and how to support them.

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.

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 drink dribble out of their mouth?

- Do they store food in their mouth for a long time?
- Do they have persistent or recurrent chest infections?

These signs could all indicate problems with the swallowing mechanism and need further assessment by an appropriate person, preferably a speech and language therapist.

At the end of life there are no right and wrong decisions about food and drink. At this stage food and drink can no longer keep someone alive, but may provide comfort and pleasure. What the person and people close to them feel is best for them is everyone's most useful guide.

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 persons 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.

Mobility

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.

It is normal for activity levels to diminish but it can be difficult for carers to decide whether this is appropriate or if there are any specific reasons why someone is having difficulties and how to support them.

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?

The environment can have a big effect on mobility and problems when discovered can usually be overcome.

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.

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 that can 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.

Complementary therapies

Complementary therapy is a term used to describe any therapy that may be seen as outside the range of orthodox or traditional medicine.

They can be used independently or used in addition and alongside medical and nursing interventions but usually not as an alternative.

Any one of the therapies can be very useful in addressing many aspects of a person needing health care, assisting to control symptoms and helping people generally to feel better, although complementary therapies cannot cure the underlying illness.

Complementary therapies include:

- Aromatherapy.
- Reflexology.
- Acupuncture.
- Homeopathy.
- Relaxation techniques.
- Hypnotherapy.
- Meditation.
- Visualisation.

How they can help

You might think that one or more of these may benefit the person you are caring for a number of reasons.

They are usually used for:

- Reduction of anxiety.
- To help control side effects of some treatments.
- To help with symptom control e.g. constipation.
- Improve circulation – this may be temporary effect.
- Relaxed muscles - this may be temporary effect.
- Promote a feeling of well being.
- To help with stress.
- It “feels nice” therefore helps people feel more positive.
- Treat the “whole person” rather than just the symptom.
- Provide quality one-one time for the person.
- Establish a positive relationship contributing to a “healing” environment.

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.

When people are at the end of life you need to be aware of:

- You must inform the doctor that you would like to try complementary therapy.
- Although complementary therapies are natural it does not necessarily mean that they can not cause harm.
- Some remedies can have side effects.
- Some remedies can interfere with conventional medicines.
- They can be expensive.
- You must use an accredited practitioner.
- You may have to inform your line manager if you work for an organisation and adhere to any policy regarding complementary therapies.



section 2 - living with dying

Relationships

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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.

- This discussion may happen in advance and could be about whether a certain treatment is given in a particular circumstance.
- This can be called an advance directive and is often about decisions refusing treatments 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 ("bring round" "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 appropriately documented in the person's notes (sometimes a specific form will be used, however this will be dependant on the care environment and policy of the organisation providing the care, the medical staff involved will be responsible for documenting decisions, however decisions should also be documented clearly in daily patient notes by the responsible person i.e. nurse, team/home leader etc. 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.

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 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 it 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 clinical 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.

Remember we all have moods and emotions and they matter!!

Breaking bad news

Breaking bad news is an uncomfortable and sometimes distressing task in any situation. Inevitably the information is sad and will draw on the emotional strength of everyone concerned.

When talking to people with learning disabilities it can be even more difficult so sometimes carers decide it is better not to say anything at all. This can be a mistake as people often sense that there is something wrong without a word being said. Protecting people in this way risks isolating them with their own fears and imagination. People with a learning disability need sensitive understanding to help them cope.

Allowing someone to talk about their feelings is important regardless of their ability to understand.

It is important to take your lead from the individual concerned and answer the questions as honestly as you can.

Always check:

- The person's understanding: this involves making sure that the person can hear and is capable of understanding. Confusion, anxiety and depression can all reduce concentration.
- The person's knowledge: this is crucial. It is wrong to assume either that they have no knowledge of the problem or that they do! Someone may ask, "Do you know why you have had those tests?"
- The person's desire to know: this is not as difficult as it sounds. A simple question may help such as, "Do you want me to tell you about the tests that you have had?"

3 reactions people could have:

- They want more information – "I would like to know".
- No more information is wanted – "I will leave everything to you, you decide".
- Uncertainty of how much information they want – "I don't know".

Things that can help:

- Find somewhere private to talk.
- Let the person control the situation, let them take the lead about the nature, quantity and depth of information discussed.
- Go at their pace, it may take more than one conversation.
- Be prepared for silence.
- Be prepared for emotion, tears, anger etc.
- Encourage the person to talk through what has already been said.
- Give the information in the most appropriate way for that person to understand, this may involve pictures etc.

Use the 3 step approach:

- **Warn:**
Carer: "we have got the results of the tests and it is not as good as we thought".
- **Pause:** wait for a response.
Person: "What do you mean?"
- **Check:**
Carer: "Do you want me to explain?"

It is very important that the person has understood the news. This approach is repeated until the person has all the information they want at that time. However, it is just as important that

they know they can come back at any time for more news or clarification. It is good practice to check the next day that they have understood.

Finally check:

- Acknowledge any distress - People worry about the emotional reaction of a person being told bad news, a reaction of any sort is normal, there may be anger, anxiety and depression, hidden or openly displayed. It is important that you know that this has happened. Ask something like “How are you feeling?”
- Is the person very distressed? – Don’t underestimate the value of your presence; time is often needed to absorb bad news. You may not have to do anything but be there.
- Is the person denying or holding unrealistic expectations? – If a person chooses not to believe what is happening this needs to be accepted as a way of coping. Don’t challenge this unless the person remains distressed and is not coping, then you would seek advice from someone more skilled in this area.

***Bad news is difficult – you can’t make the news less bad,
but you can avoid breaking it badly!***

Adapted with permission from Regnard C, Hockley J. A Guide to Symptom Relief in Palliative Care. 5th ed. Oxford: Radcliffe Press, 2004.

What is palliative care?

Mainstream palliative care services should be available to people with learning disabilities, however for clients with severe disability or additional behaviour or mental health needs this is not always possible. For this group their learning disability and additional needs may cause problems when accessing palliative care services:

- An individual's palliative care needs may not be recognised due to the complexity of their problems.
- Staff and mainstream services may not understand the person's channels of communication.
- Staff and mainstream services may perceive people with learning disabilities as disruptive or non-compliant.

These concepts occur through lack of knowledge, understanding and education.

What is palliative care?

Palliative care is the total care of patients whose disease no longer responds to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount.

The goal of palliative care is achievement of the best quality of life for patient's, families and carers.

Philosophy of palliative care:

- Affirms life and regards dying as a normal process.
- Neither hastens' or postpones death.
- Provides relief from pain and other distressing symptoms.
- Integrates the psychological and spiritual aspects of palliative care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help families and carers to cope during the patient's illness and into their own bereavement.

The elements of palliative care

Palliative care has been described as "Compassion with competence".

There are 4 components:

- Physical.
 - Psychological.
 - Social.
 - Spiritual.
- } key factor is communication

When should someone receive palliative care?

- Palliative care may begin at any time from the point of diagnosis to death, although it is more usual for it to start when a cure is no longer possible.
- In people with learning disabilities diagnosis is often made late hence the disease is no longer responsive to curative treatment, in this instance Palliative Care begins at the point of diagnosis.
- Again in diseases which have a rapid progression it may be necessary for the person to have palliative care interventions from diagnosis.

Where should it happen?

- At home.
- In hospital.

- In a hospice.
- In nursing homes.

It is the right of every person with a life threatening / life limiting illness to receive palliative care wherever they are.

Distinctions:

- **Specialist palliative care:** is provided in specialist units and by teams of professionals with specialist palliative care skills and accredited education qualifications in Palliative Care. Skilled, multi professional teams where staff are also accredited specialists having undertaken the requisite education required.

Supportive care: uses the principles of palliative care and should be used by everyone caring for a patient nearing the end of an illness. It is an integral part of all clinical practice and is the right of every patient and the duty of every professional.

- Focus on quality of life which includes good symptom control.
 - Is a whole person approach.
 - Care which encompasses both the person AND the people who matter to them.
 - Respect for autonomy and choice.
 - Emphasis on open and honest communication.
- **Palliative procedures and techniques:** are important aspects of palliative care. They include radiotherapy, chemotherapy and surgical procedures and other services such as those offering psychosocial care.

Helping people to understand:

Learning disability staff may feel:

Threatened
Dis-empowered

Palliative care staff may feel:

Threatened
Dis-empowered

People have to work together to provide the best care possible at a very difficult time.

Adapted with permission from Regnard et al, What is Palliative Care? In, Helping the person with Advanced Disease: a workbook. Oxford: Radcliffe Press, 2003.(Also available as CLIP-Current Learning In Palliative Care-workshops on WWW.helpthehospices.org.uk

Religion, culture and spiritual needs

It is often presumed that people with learning disabilities do not have any religious, cultural or spiritual beliefs. This is obviously not true in that, just as with the general population, there will be some people who have strong beliefs, some who do not and some who don't know.

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

People may want to have particular practices carried out or certain prayers read and hymns sung. It is important to do whatever is right and most helpful for the person.

Different approaches

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 "its 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 they way we were brought up, the customs that have been passed on from generation to generation. This can be customs and practices, religious or otherwise. We all have family rituals that we do because "that's the way its always been done" in the family e.g. People open Christmas presents at different times of the day, or celebrate birthdays in different ways. We must realise that people with a learning disability will have been brought up with family "rituals" and carers must try and support the person to maintain these.

In reality spirituality and religion can get all mixed up. However the main thing is to respond to people as individuals.

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. Most people in this country identify themselves by their "given" or Christian name followed by their surname but this is not universal practice, 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 e.g. Muslims and Hindus prefer to wash in free flowing water rather than sit in a bath.
- Modesty – this is an area that needs to be treated with the greatest respect at all times however, there are sometimes special considerations that need to be taken into account e.g. 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.

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, don't assume someone with a learning disability will not have it, 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” however 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.
- If in any doubt seek advice.

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 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.

Even in cardiac and respiratory failure, sudden, dramatic deaths are uncommon.

- 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.

What you can do:

- 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 so he/she can 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.
- Contact the undertaker and explain any expressed wishes for the funeral.
- 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.
- Register the death at the local registrars 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.
- Find out if any Advanced order is in place e.g. “Do not Resuscitate”.
- Find out if the person has an advocate or independent consultee who may be required to help make decisions.
- Planning when the end is imminent helps everyone.

Adapted with permission from Regnard et al, “The last hours” In, Helping the person with Advanced Disease: a workbook. Oxford: Radcliffe Press, 2003.(Also available as CLIP-Current Learning In Palliative Care- workshops on WWW.helpthehospices.org.uk)

When a friend dies

Every person will experience loss and bereavement at some point in their lives, but many people shy away from discussions involving death and dying. This tendency to hide death results in several typical practices at the time of death such as closing the curtains, talking in whispers and not telling fellow patients or residents.

This reluctance to share loss results in other residents and staff suppressing their grief and having feelings of uncertainty, tension and fear.

People may try to protect other people with a learning disability who know the person who has died from the effects of grief, this can unintentionally make things worse.

What you can do:

- Be honest, this is the best place to start.
- Take time to sit and talk with the person including those who do not communicate using recognised methods such as speech.
- Don't try and "jolly" the person along. It is normal to be sad and hurt.
- Help the person bring back good memories of the person who has died which would have been forgotten. This is significant and can be seen as a vital element in helping the person. Ask the question: "Do you remember.....?"
- Remember that grief may take time to manifest itself.
- Be prepared to have the conversation more than once, it may take time for someone to realise and accept what has happened.
- Ensure that the person who has lost their friend is given support while adjusting to living without them.
- Keep ideas and conversation simple and concrete.
- If you feel sad and are upset don't try and hide it, this will reinforce that this is a normal grief reaction.
- If the people in the house are laughing about something reinforce that this is fine, you shouldn't feel guilty about living.

Things that might help:

- Support the person to go to their friend's funeral, this will help them realise that their friend has died.
- Support them to choose flowers or a card and either take them to the funeral or send it to relatives.
- Help them to choose a hymn or piece of poetry to be read at the funeral.
- Support them to actually take part in the service if appropriate.
- Suggest that they help plan and prepare for a "tea" after the funeral or if that is not appropriate at another date.
- Let them choose something to keep that belonged to the person who has died.
- Help the person make a memory box or life storybook about the person who has died.
- Make a photo collage of that person for the house or their room.
- Talking about the person remembering good and bad times.
- Allow people to continue to do things that they enjoy if that is what they want to do.

Historically it is believed that people with learning disabilities were not capable of understanding or expressing grief, whether through ignorance or a misguided attempt to protect the person the death of a relative or friend was often glossed over. Sometimes relatives and carers hid their true emotions from the person with a learning disability.

People with learning disabilities have the same reactions to grief that we do, some may express it differently.

In short how should we treat people with learning disabilities following the loss of one of their friends? The answer is easy – like any other person!!

Ref: Blackman N., Todd S. Caring for people with learning disabilities who are dying (2005)
Worth publishing.

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.
- 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. (e.g. If it is an expected death and it occurs at 2am then the GP may wait until the beginning of surgery. English law does not require the doctor to confirm death, view the body or report the fact that death has occurred. In the event of an anticipated death the input of a doctor is only required when convenient for certification: (REF: GPC (General Practitioners Committee). Confirmation and Certification of Death: Guidance for GPs in England and Wales London BMA, 1999).
- 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 you have the death certificate contact the funeral director (they provide 24hour 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, you can arrange this yourself if you want or they can do it for you.
- You need to know any expressed wish of the deceased person, e.g. did they want to be buried or cremated?
- 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.
- You need to take the death certificate, the birth certificate and if applicable the marriage certificate to the registrars office in the sub district where the death has occurred. If you do not have a birth certificate, you need to:

- If there are no known relatives contact the medical records office of the organisation you work for.
- If there are relatives contact them.
- The registrar will give you a certificate of burial or cremation (also known as a green form).
 - You give this to the funeral director.
 - They will also give you a certificate of registration of death form (BD8).
 - You will need this for social security purposes.

Other pertinent people:

- You will have to inform your line manager / locality manager / point of contact if you work for an organisation.
- The consultant in charge of the case (possibly the psychiatrist in many cases).
- Friends of the deceased.
- Clergy.
- Care manager if they had one.
- Any other professional who was involved.
- If applicable, previous homes that the deceased lived in.

Some of these contacts can be done in the days following the death.

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.

One person does not have to do all the tasks however one person does have to take the responsibility to see that they have been done. It may be useful to make a checklist of the relevant people to be informed.



section 3 - challenges and solutions

Challenges
Financial Support
People who can help

Challenges for carers

Providing end of life care for people with a learning disability can present problems for professionals and other staff in diagnosing appropriate treatment and in developing the correct approaches. This is particularly so for people with a learning disability and those who do not use ordinary speech as we would.

It is important to have good links with staff working in all areas across mainstream services. However, sometimes there can be misunderstandings and poor awareness of the needs of people with learning disabilities that can be both frustrating and upsetting for the person with learning disabilities their carers and staff within mainstream services who provide treatment/interventions as quite often they lack knowledge and experience of caring for people with learning disabilities.

This is a brief summary of some of the challenges that may affect care at the end of life and it aims to highlight, that as someone supporting a person with learning disabilities you may have to challenge services/professionals on behalf of the person with learning disabilities at times when you feel they maybe don't receive the care/treatment options that are given to the mainstream population.

These challenges can be roughly grouped together as the 5 C's:

- **Complexity.**
- **Communication.**
- **Compliance.**
- **Consent.**
- **Choice.**

Complexity

Often people who work in the general health services have never met anyone with a learning disability before and can have problems seeing beyond the learning disability and possible physical issues. This can cause problems with assessments, not identifying problems correctly and then giving an inappropriate programme of care or worse no care at all. It can be described as not seeing the wood for the trees.

What can you do?

If you know that someone is coming to see the person you care for or they have to go for an appointment:

- Have all the information ready, this could include many things, e.g. BP, weight, etc. (if recorded regularly, this may be dependant on the care setting in which the person lives) This could all be written down on 1 sheet.
- Have someone present who knows the individual really well.
- Have a clear history of the problem or issue written down with relevant dates documented. You will be asked questions like "How long has he been vomiting?" It is much better to say something like "we first noticed it on 2nd June" rather than "about 3 months".
- Be prepared for questions like: "Has he/she been sick?" You cannot just say yes, you need to know what time of day, how many times, was he ok afterwards, maybe even what did it look like and the quantity of vomit! Detail is important.
- Let the person who is doing the examination know what is "normal" for the person with learning disabilities.
- Keep the person dressed in clothes that are easy to take on and off.
- If you don't understand what is going on, say so!
- Before you leave the appointment check your understanding of what has been said with the doctor to ensure the information is clear in your mind. This will be important so that the correct information can be relayed to relevant people.
- Ask for an appointment at the best time of the day for the person who you are caring for if that is possible.
- Ask for a "double" appointment if you think that discussion and assessment of the person will need extra time.

Communication

Many people with a learning disability do not communicate using ordinary speech as we do.

- Some people can have good use of words but have problems understanding the meaning of them.
- Some people use non-verbal communication that can include any or all of the following, gesture, sounds, expression, habits, mannerisms, and certain behaviours, this group of people:
 - May have difficulty in understanding what is being said OR
 - Have a very good understanding of what is being said to them.

This can result in people making assumptions regarding an individual's ability to communicate effectively.

To communicate we both send and receive messages and to do this most of us use words AND non-verbal cues. Therefore, it could be said that all behaviour, regardless whether it is positive or negative is a way of communicating.

People who are not used to working with people with learning disabilities often misinterpret these signals as negative behaviour and possibly miss vital information that would help them to care for people with learning disabilities at the end of their life. They also do not understand how to communicate things TO the person and that can lead to frustration for all concerned.

What can you do about it?

- Always ask the health care staff to “talk to “ the person you are supporting.
- Ask the health care staff to use the person's name when talking to them.
- Ask them to use short sentences with a little information at a time.
- Tell them to say what they mean, don't use confusing expressions such as “it's raining cats and dogs”.
- Ask staff to talk to the individual at eye level, that is if the person is a wheelchair user people shouldn't hover over them.
- Learn the language that the person you are caring for uses. This may sound silly but it is up to you to know it otherwise how can you help? Like any language you need to know:
 - What the words mean.
 - Learn the basic vocabulary.
 - Know how the words are put together.
 - Make sense of what the person is “saying”.
- Know the person you are caring for very well. This is the only way to learn the language.
- Talk together as a team so that all parts of the person's language is learned, different people may pick up different bits of the “vocabulary”.
- Document this using a tool such as DisDAT, if something is written down, it makes what you know instinctively explicit to others.
- Observe and record any change in the way the people you are supporting are behaving, it may actually be an absence of the behaviour that means they are more poorly.
- Don't allow health professionals to presume they are right, if you disagree with what has been said, or firmly believe that the person you are supporting is trying to tell you or them something then discuss this with the professionals involved.

Ref: See www.mencap.org.uk for latest version of DisDAT.

Challenges for carers - compliance

Many health care professionals may use this word when talking about people with learning disabilities, “he will not comply with the treatment” “she will not comply with the scan”, “he will not comply with the programme of care needed after surgery” and because of this sometimes people with learning disabilities may not always be offered the necessary interventions or investigations or be considered for treatment appropriate to their condition.

Health care staff within mainstream services often have no or limited experience of people with learning disability and presumptions are therefore often made about the person’s quality of life, and their ability to undertake investigations and treatments.

There are often quite simple solutions to this, however in these situations a great deal of time, thought and planning is necessary and this will include involvement with all people who care for, as well as those being responsible for the care given to the person with the learning disability.

Basically very little is impossible if people work together, where there is a will there is a way.

What can you do?

- If the doctor or health care professional tells you that further investigation or treatment would help but it can’t be done ask why? Is it because of technical problems with the machine? Is it because the doctor feels the person wouldn’t be able to comply with the procedure? We can’t repair machinery but we can discuss options which may be helpful in ensuring the person can access the appropriate investigations or treatments e.g. X-ray, Scan (there are various types) blood tests, radiotherapy, chemotherapy.
 - Additional time to plan and attend appointments should be considered.
 - Explanations of procedures / treatments to the person with a learning disability - this needs to be given at a level appropriate to the person’s understanding.
 - If a person has very limited understanding then decisions need to be made for them with regard to investigation/ treatment in this instance the provision of reassurance, support and comfort are the main aims, this will enable the person to feel safe and provide security during investigations/treatments.
 - Sometimes it is necessary for people undergoing investigations to be given medication to help them feel less anxious. People with learning disabilities are no different, however they may also need some medication to help them undergo basic investigations e.g. blood tests, scans etc If this is thought to be necessary then discussion regarding the most appropriate medication needs to be held with the person’s doctor - GP, Consultant, Consultant in Palliative Care Medicine, the care team should also be involved in this discussion.

Challenges for carers - consent

Health professionals, social care staff and families supporting people with a learning disability are often unsure about the law on consent and about the capacity of someone with a learning disability to consent to examination or investigation or treatment.

It is good practice for everyone to think carefully about consent and how to give people information in a way appropriate to their level of understanding so that they can decide what they want and how they can express their wishes.

The issue over consent can cloud many aspects of caring for someone with a learning disability even at the end of life. Many health care professionals will ask for a carer to sign a consent form or even not consider seeking consent because the person has not got capacity to consent. This can make an already very difficult time for someone supporting the person worse.

The legal issues around consent can be complex but sometimes they can be made more complicated than need be.

Key points:

- The law assumes that everyone over the age of 18 has the capacity to consent or agree to a procedure or treatment.
- No one can consent to or refuse treatment on behalf of another adult who lacks capacity to consent. This will change slightly in April 2007 when the Mental Capacity Act is implemented. Then a “decision maker” can be appointed but they must follow certain principles. (You may need to seek further advice).

Ref: www.doh.gov.uk/consent

- There is a common law duty for doctors and other health professionals to provide treatment to adults who do not have the capacity to consent IF that treatment is necessary and in their best interests.

What you can do:

- Talk to the person with a learning disability; don't assume that they cannot understand what is going on.
- Give the person with a learning disability the information they need in whatever format they understand best. This may be pictures, symbols, video tapes etc.
- Actually “practice” anything that is possible to do. E.g. if someone needs an x-ray ask if you can take the person to the x-ray department and ask the staff to do “dummy runs”.
- As Individuals' it is sometimes difficult for us to understand a lot of new information given at one session, such as during an appointment with a doctor. For people with a learning disability this can be a very difficult scenario, especially if they are asked to make a decision “on the spot”. If you feel that this is happening for the person you are supporting, ask the doctor if they can have a follow up appointment where information can be repeated, or a series of appointments so that the person with the learning disability can contribute to the decision making process to the best of their ability.
- Ask if a specialist nurse or other professional can come to the person's home to discuss options in a less formal or frightening environment.
- Ask the doctor or health care professional questions like “What would you consider / do if it was me?”
- Ask a relative or friend of the person to help with the discussion but this must be unbiased.
- No one should make a decision on their own, if the person with a learning disability is unable to make the decision for them, a team should discuss the pros and cons with relatives if there are any.

- Ask an advocate to help – these people act on behalf of the person with a learning disability and will work in an objective manner.
- If there are disagreements regarding the decision you can ask for an Independent Mental Capacity Advocate (IMCA) (will be available nationally by April 2007) to support and represent the person with a learning disability who lacks capacity.

Families and carers can be great advocates for the person with learning disability's health, but they all need to be well informed too.

Do not be frightened to ask questions on behalf of the person you support and do not be frightened to challenge if you think the decision being made is wrong.

Challenges for carers - choice

Knowing what to expect when someone is nearing the end of life is really important both for the person who is ill and his or her families and carers. This may involve having to make some important choices about difficult subjects or may focus around every day activities that someone else is deciding for you thus taking control over what life you have left and how you live it.

At this stage in life anyone may feel that they have less choice than they did have when they were well and this can be even more difficult for people with a learning disability who usually have less choice than most people.

It is the responsibility of the people who support them to keep offering choices and when certain choices are being removed, to act on their behalf.

How can you help:

- Talk to the person, give them time to talk to you, it may be uncomfortable for you to talk about certain subjects but it is important to try as they may have very definite wishes.
- Allow them to continue with activities they were used to, if they want to go out in the mini-bus with their friends let them as long as there are no medical reasons why not.
- People may need extra support to help them continue their daily lives and social activities, this may mean services need to examine staffing levels and increase support in the care environment as needed.
- Let the person have as much choice in everyday matters as possible, don't assume that because they are poorly that it is best that they stay in bed, they may prefer to get up and sit in the living room with their friends. It can be very lonely lying in bed hearing people moving around and talking in another room.
- The person may want to make choices about his/her funeral, a special hymn or a special place. It can be uncomfortable but it should be discussed again using the format the person understands best.
- Where does the person want to die? This does need to be discussed and if the person cannot make that decision then the people who support him/her need to have plans. The 3 main options are:
 - At home – this is always an option for most people but for the person with a learning disability it can be made to feel difficult especially if the person has developed nursing needs and live in a community home that has been registered as residential. This can be overcome by having a discussion with the Commission for Social Care Inspection (CSCI) inspector who will be very helpful in explaining what can be done.
 - At a hospice – a person with a learning disability has the same rights to access hospice care as anyone else, however, like anyone else, can only go to one if there is a bed available. This will need careful planning with the doctor and/or Macmillan nurse.
 - At a hospital – many people are admitted into hospital at the end of life when they require 24-hour medical supervision or symptom control is poor. It sometimes occurs when planning has been poor and people are admitted in a crisis situation. For some people and their families this is a good option, as it feels “safe”. Consideration should be taken with the person with a learning disability that they do not become more frightened in this scenario as it may be a strange situation.
 - It matters less where we die, than how we die, so whether a person dies at home, in a hospital or hospice the important thing is to make sure they feel loved, comforted, safe, and secure. We can help this to happen, in supporting the person and providing familiarity of carers in any environment - alongside district nursing, hospital or hospice staff. This will also help carers in the bereavement process when they reflect on providing care to the person at the end of their life and into death.

- Who do they want with them at the end? Some people have “favourite” staff and they may choose to have them there and obviously some family members. Sometimes a person with a learning disability is unable to make this decision, this may be due to the complexity of their learning disability or may be related to their advanced illness, so we must decide on their behalf taking into account their likes/ dislikes in life in order that they may die as peacefully as possible feeling loved and secure.

The most important point is to keep offering the person choices and to follow them out if practical.

Major choices that are made need to be told to everyone, the family, the staff team, the local GP practice and to any other pertinent person so that the person's wishes are upheld.

Financial support

When someone is ill and nearing the end of life they may have extra expenses. There are various types of financial help or benefits that individuals are entitled to and this is worth exploring.

Benefits

The benefits agency has two booklets (IB1 and SD1), which outline ALL social security benefits.

You can get copies from:

- Local citizens advice bureau website www.citizensadvice.org.uk
- Local social security office.

Advice and information is also available from:

- Benefit enquiry line – Freephone 0800882200.
- Department for Work and Pensions website www.dwp.gov.uk

People (under 65) may qualify for **Disability Living Allowance (DLA)** or if they are already in receipt of this they may qualify to receive it at a higher level.

DLA is made up of:

- Care component – for difficulties with looking after yourself.
- Mobility component – for difficulties with walking. This gives an automatic entitlement to a Blue Badge parking concession and, if a car is used for the individual an exemption from road tax.

People (over 65) may qualify for **Attendance Allowance (AA)**. Your local security office can send you claim forms and guidance.

People can claim Disability Living Allowance or Attendance Allowance even if they are working, and also if no one actually gives them practical help.

If an individual claims DLA or AA and has someone looking after them, they may be able to claim.

There is a **fast track claim** for these 2 allowances for people that are **not expected to live for more than 6 months**. If people think that this “special rule” applies, the individual’s doctor needs to complete an extra form as well as the application form for either benefit.

It is always difficult to tell exactly how long someone may live and many people with advanced disease may be entitled to this benefit, so it can be helpful to check with the doctor. Claiming it does not mean that they will live less than six months.

Carer’s Allowance: to qualify for this someone has to care for another person for at least 35 hours per week. You can work but there is a weekly earnings limit.

Other financial help

Occasionally financial support can be given by some charities, trusts or organisations to individuals.

Grants

You may also be able to claim grants and benefits from other organisations or charities. To ease financial pressure **Macmillan** award one off **grants** for a wide variety of practical needs.

People qualify if:

- They have cancer.
- Savings are no more than an determined limit (currently £6,000 for single people).
- The household has a weekly income of up to £100 per person after payment of certain bills.

There is a financial advice line for further advice:

Freephone 0808 8010304

They also have a booklet called:

Help With the Cost of Cancer

Your local Macmillan nurse can also advise, as applications must be made through a Macmillan nurse or social worker.

Cancerbackup can also give advice regarding financial support:

0808 800 1234

The Association of Charity Officers is an organisation that tries to help individuals to find specific charities that may be able to offer some financial assistance. Using information about you such as your occupation, where you live, your religion and your type of cancer it is usually able to find relevant charities. It can be contacted on 01707 651 777, or via the website www.aco.uk.net.

A book that gives details of all the trusts and organisations that provide financial support to people in the UK is available from bookshops or local libraries:

A Guide to Grants for Individuals in Need 2004/2005. By A. French, D. Griffiths and E. Jepson. Published by Directory of Social Change (2004). ISBN 1903991528. Priced £29.95.

Your local library may have a copy.

Help with NHS costs

If people are on a low income they may also be entitled to help with NHS costs, including travel for hospital treatment, dental treatment, prescriptions, wigs, glasses and sight tests.

You can get information about these benefits from your local Social Security office, the Benefit Enquiry Line (0800 882200) or the Department for Work and Pensions website (www.dwp.gov.uk).

You are automatically entitled to free prescriptions and do not have to pay other NHS costs if you:

- Are over 65.
- are under 16.
- are aged 16–19 and still in full-time education.
- claim Income Support or some other benefits.
- are pregnant or have had a baby in the last 12 months.
- have a war or Ministry of Defence Disablement Pension and need prescriptions for a war injury.
- have particular long-term medical conditions – details of these are given in leaflet HC11 which you can get from the Social Security office.

Unfortunately, cancer itself does not entitle you to free prescriptions, but you may be eligible for other reasons.

If you are not automatically entitled to free prescriptions, but are on a low income you can apply on form HC1 for a certificate for free services or reduced charges.

If you need a lot of prescriptions but cannot get them for free, you can cut costs by buying a pre-payment certificate for four months or a year. You save money if you need more than five prescription items in four months, or more than 14 items in a year. You can get a claim form (FP95) from your GP, your health authority or main post offices. Ring 0845 850 0030 to buy a pre-payment certificate over the phone using your credit or debit card.

If you have a disability caused by your illness or its treatment, you may be able to get further help such as special equipment put into your home (eg ramps or hand-rails), bus and train concessions and a special key to give you access to toilets for disabled people. You can get details of these schemes from your local Social Services office.

People who can help

The District Nurse

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

As well as providing care for patients, district nurses also have a teaching role, working with patients to help them to care for themselves or with family/carers teaching them how to give care to their relatives.

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 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 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.

District nurses work in collaboration with other health care professionals to provide best quality care for patients i.e. Hospital teams, Macmillan/Marie Curie Nurses, Occupational therapists, physiotherapists, and pharmacists.

People who can help

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. 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 ie hospice services, day hospice care.
- Co-ordinate an individuals care through working closely with primary care teams and others involved in the patients 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:

- Patients and their families.
- Medical staff.
- Other MacMillan nurses/physiotherapists.
- Specialist nurses.
- Community learning disability nurses.
- District nurses.
- Social services.
- Allied health professionals.

When/why you might refer:

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

Macmillan nurse contact numbers:

Cleveland 01429 855 556

Darlington 01325 465 564

Durham Dales 01388 607 301

Durham and Chester le street 0191 387 6533

Easington and district 0191 586 2426

Hartlepool 01429 267 901

Middlesbrough and Langbaugh 01287 639 100

Newcastle 0191 226 1315

North Tees 01642 624 112

North Tyneside 01912205955

Northumberland Dorothy Matthews

01670 394 808/ 0776 680 0461

Northumberland Central 01670 304 713

Northumberland North 01665 626 713

South East Northumberland 01670 712 238

South Tyneside 01914516396

West Northumberland 01434 604 008

People who can help

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, aging, disease or disability by using physical approaches.

Physiotherapists work in a variety of health settings including hospitals, health centres, GP practices, schools 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.
- Liase 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.

Physiotherapy contact numbers:

Newcastle 0191 210 6868

North Tyneside 0191 200 1077

Northumberland 01670 394 260 or 01661 514 570

South Tyneside 0191 483 5560

Sunderland 0191 565 6256

People who can help

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.

Occupational therapy contact numbers:

Morpeth 01670516131

North Tyneside 0191 259 6660

Northumberland 01661 839 170

Northumberland Central 01670 810 600

Northumberland North 01665 573 006

Northumberland West 01661 839 170

Sunderland 0191 565 6256

South Tyneside 0191 4835 5560

People who can help

Speech and Language Therapist (SALT)

A Speech and Language Therapist is a health care professional who work with people with communication and / or eating, drinking and swallowing difficulties.

They will assess, treat and make recommendations and suggestions pertinent to the client and their carers.

Speech and Language Therapists work in a variety of settings including hospitals, health centres, schools and GP practices and also visit people in their own homes.

How they may help in end of life care:

- Assessment of communication skills.
- Advice on methods of communicating other than words e.g. Makaton.
- Advice on accessible information.
- Assessment of eating, drinking and swallowing.
- 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 Speech and Language Therapist?

- Speak to your GP.
- Speak to your care manager / community nurse / community team.
- Contact your local Speech and Language department.

SALTs contact numbers:

Newcastle 01912106868

North Tyneside 0191 293 2712

Northumberland 01665 573 006

People who can help

Dietician

A dietician is a health care professional who can translate the science of nutrition into 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 suitable 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.

Dietician contact details:

No specific dietician for learning disabilities – an individual would access generic dietician via referral from GP.

People who can help

Care Managers / Community Nurses / Social Workers

These professional roles have been put together as they can all work in both a practical and/or advisory way. They may be involved with a client in a very specific role or they may work in a co-ordination role.

Care Managers

These people act as the gateway to services. Not every area has care management, however, if this model is used a care manager can be from a number of professional backgrounds, usually nursing, social work or occupational therapy. They provide assessments of the practical aspects of a person's life and usually coordinate a "package of care". A care manager will be allocated a person to work with, then will make sure that the individual gets the services he/she requires in a timely manner.

How they can help?

- Assessments.
- Coordinate care.
- Advice on appropriate accommodation.
- Ensure that the individual is getting the benefits that they are entitled to.
- Arrange support / transport to key appointments.
- Support the individual their families and / or carers.
- Liaise with other professionals.

Social workers

These people can provide emotional and psychological support especially at difficult times in people's lives. They always 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 as a social worker.

How can they help?

- Assessments.
- They can facilitate:
 - Social inclusion.
 - The persons 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.
- Liaise with other professionals.

Community nurses

These people are registered nurses, therefore, usually provide practical help although can also provide support in many situations. They can act in coordinating role, especially when different agencies and medical staff are involved.

How they can help?

- Assessments.
- Identify when someone is not managing as well as they could and co-ordinate the pathways of care necessary to find out why.
- Coordinate medical care.
- Help the person complete a health action plan.
- Support the individual families and/or carers.
- Practical interventions/programmes of care.
- Accompany/arrange support when people attend appointments.
- Liaise with other professionals.

Care Managers/Community nurses LD/ Social Workers contact numbers:

Blyth 01670 798 930

Morpeth 01670 810 600

Newcastle 0191 210 6868

Northumberland Central 01670 810 600

Northumberland North 01665 573 006

Northumberland West 01661 832 758

North Tyneside 0191 200 1077

South Tyneside 0191 4835 5560

People who can help

Advocate

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. A person's initial hopes and dreams can be severely limited by this and this can be the case for many of the people we support with learning disabilities.

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.

Independent advocacy:

- Advocacy can be provided by both paid and unpaid advocates.
- The aim is to support people to represent their own interests, if this is not possible the advocate will represent the person's views.
- The advocate provides support on specific issues.
- They provide information NOT advice.
- Support can be long or short term.
- Independent advocates can support more than one person at a time.

How they might help at the end of life:

- Help in difficult decision making discussions.
- Help with legal issues Independent Mental Capacity Advocate (IMCA).
- Help the person express their fears, wishes, hopes.
- Help the person maintain the lifestyle he/she would like.

How to find an advocate:

- Speak to your community nurse.
- Speak to your social worker/care manager.
- Speak to your organisation.
- There is a range of independent organisations such as:
 - Skills for People.
 - Newcastle Advocacy Service.

Advocacy contact numbers:

Skills for People, Newcastle 0191 281 7322
Gateshead 0191 478 6472
Newcastle 0191 232 7445
South Tyneside 0191 427 4583
Darlington 01325 465 337
North Tyneside 0191 2596 662

Northumberland 01670 535 000
Sunderland 0191 514 1291
Redcar & Cleveland 01642 835 149
Middlesbrough 01642 835 149
Stockton 01642 835 149
Hartlepool 01642 835 149



part 4 - useful information

Useful tools in End of Life Care
Useful sources of information

Useful tools in end of life care

The End of Life Care programme has been implemented as a national initiative, which aims to improve care for all individuals nearing the end of their lives regardless of their diagnosis, enabling them to die in a place of their choosing.

In providing End of Life Care it is necessary to assess an individual's needs and monitor their symptoms in order that their End of Life Care will be individual, appropriate and effective.

There are many useful tools that enable us to provide "good" End of Life Care:

Liverpool Care Pathway for the Dying (LCP)

Once a person is thought to be in the last hours and days of their lives a decision may be taken by medical and nursing staff in discussion with the patient's family/carers to use the LCP.

For the LCP to be implemented the person will have two out of the four following problems:

- The person is bed bound.
- Is only able to take sips of fluids.
- Is no longer able to take tablets.
- Is semi comatose.

This document has three main sections:

- Initial assessment and care.
- Ongoing care.
- Care after death.

The professionals providing End of Life Care will co-ordinate and manage all aspects of implementing and monitoring the pathway for the patient.

Preferred Place of Care (PPC)

This tool is used to record patient's and carer's wishes in relation to their care and where they would choose to die; this is very useful information to have when care is being planned.

The PPC records services that are available in the area where a person lives and what services the person is accessing. The tool also highlights any changes in a person's choice/place of care and the reasons for the changes.

Benefits of using the PPC are:

- Creates choices for patients and families.
- Choices and changes are recorded.
- Care provided is monitored.
- Highlights positive and negative aspects of resources/services, which can be useful in planning for future services. For advice regarding PPC documentation see your district nurse or Macmillan nurse.

DisDAT (Disability Distress Assessment Tool) – this is a documentation tool which allows an individual's distress to be identified through changes in their usual behaviour.

Once distress has been identified it needs to be put in context and then clinical decisions applied by the team caring for the individual to decide the likeliest cause of the distress and appropriate interventions to alleviate it, there are also monitoring sheets for use with the tool, these can help in finding out the severity of the distress and if there is any pattern to it. DisDAT is particularly useful for individuals who use alternative communication i.e. gestures, body language, eye contact etc.

For the latest version of DisDAT see www.mencap.org.uk or contact Dorothy Matthews, Lynn Gibson or Claud Regnard.

Diet and fluid monitoring forms – these can be useful in recording how much food/drink a person is being offered and how much they are able to accept. In end of life care the focus is not on eating to survive but in eating for pleasure, small tastes and drinks are often more acceptable to people at this time in their lives, however it can be useful to have a record of a person's food/drink intake when health professionals are looking at the person's condition and deciding changes to treatments and overall management of the patient.

Your district nurse / community nurse/ Macmillan nurse can give advice regarding the relevant forms.

Pressure ulcer risk assessment forms – these are a useful tool in deciding how at risk a person is of developing pressure ulcers. People in end of life are quite often at high risk of developing pressure ulcers due to their deteriorating condition. These tools score the patients risk and are useful when planning equipment and level of care a person needs.

Your district nurse / community nurse/ Macmillan nurse can give advice regarding pressure ulcer risk assessment.

Epilepsy monitoring forms – these are used to record frequency and severity of seizures, people develop epilepsy for many different reasons, some people will have suffered seizures most of their lives, for others it is often a consequence of their disease i.e. seizures are often a very problematic symptom in end stage downs syndrome related dementia, they are also common in people who have certain kinds of tumours.

These forms are useful in reviewing medication to control seizures in order to promote the comfort of the patient.

Your district nurse / community nurse/ Macmillan nurse can give advice regarding the relevant forms.

Useful sources of information

The following list is based on suggestions rather than being exhaustive – please add your own useful contacts.

Aging

Help the Aged
Tel: 0207 278 1114
www.helptheaged.org.uk

Age Concern
Tel: 0208 765 7200
www.ageconcern.org.uk

Darlington 01325 262 832
Gateshead 0191 477 3559
Middlesbrough 01642 805500
Newcastle 0191 232 6488
North Shields 0191 280 8484
Northumberland Tel: 01670528220
South Shields 0191 456 6903
Sunderland 0191 514 1131

Bereavement

Macmillan Bereavement Service
Northumberland 01670 717 434 Carole Sullivan
North Tyneside 0191 297 9013 George Berry

Cruise Bereavement Care
Tel: 08701671677
www.crusebereavementcare.org.uk

Cancer

Marie Curie Cancer Care
Tel: 0207 599 777
www.mariecurie.org.uk

Macmillan Cancer Support
Tel: 0808 808 2020
www.macmillan.org.uk

Cancerbackup
Helpline 0808 800 1234
www.cancerbackup.org.uk

Cancer Research UK
Helpline: 0800 226 237
www.cancerresearchuk.org

Care Homes

The English Community Care Association
Tel: 0207 220 9595
www.ecca.org.uk

Registered Nursing Home Association
Tel: 0121 454 2511
www.rnha.co.uk

The National Care Forum (NCF)
Tel: 0247 624 3619
www.nationalcareforum.org.uk

National Care Association
Tel: 0207 831 7090
www.ncha.gb.com/ncha/index.htm

Carers

Carers UK
CarersLine: 0808 808 7777
www.carersuk.org
Email: info@carersuk.org.

Princess Royal Trust for Carers
Tel: 0207 480 7788
www.carers.org

Darlington Carers Support Service 01325 357 533
Gateshead Carers Centre 0191 490 0121
Hartlepool Carers Centre 01429 283 095
Middlesbrough Social Services Contact Centre 01642 726004
Newcastle Carers Centre 0191 260 3030
North Tyneside Carers Centre 0191 200 1111
Northumberland Carers Office 01670 394 400
Redcare and Cleaveland Carers Together 01642 488977
South Tyneside Carers Association 0191 454 3346
Stockton Carers Centre 01642 739955
Sunderland Carers Centre 0191 567 3232

Dementia

Alzheimer's Society
The Alzheimer's Society
North East Area Office Tel: 0191 217 3810
Helpline: 0845 300 0336
www.alzheimers.org.uk Email enquiries@alzheimers.org.uk

For Learning Disabilities and Dementia information sheet
www.alzheimers.org.uk/pdf/i_learningdisabilities.pdf

Alzheimer's Disease International
For Factsheet on Learning Disability and Dementia.
Alzheimer's Disease International,
Tel: 0207 620 3011
www.alz.co.uk

Scottish Down's Syndrome Association
Tel: 0131 313 4225
www.dsscotland.org.uk Email: info@dsscotland.org.uk

Department of Health
www.doh.gov.uk/learningdisabilities/access/section_7.htm

Financial Advice

The Citizens Advice service
www.citizensadvice.org.uk

Finance
Age Concern information line: 0800 009 966

Benefit Enquiry Line 0800 88 2200
Confidential advice and information for people with disabilities, and their carers and representatives, about social security benefits and how to claim them

Attendance Allowance and Disability Living Allowance general enquires 0845 123 456

Carer's Allowance general enquires 01253 856 123

Pension Service general enquires 0845 60 60 265
www.thepensionservice.gov.uk

Counsel and Care
Tel: 0207 241 8555
www.counselandcare.org.uk

The British Red Cross
 Tel: 0870 170 7000
www.redcross.org.uk

Hospice Care/Palliative care

The National Council Palliative Care
 Tel: 020 7697 1520
www.ncpc.org.uk

Help the Hospices
 Tel: 0207 520 8200
www.helpthehospices.org.uk

Hospice Information
 Tel: 0207 520 8232
www.hospiceinformation.info

Darlington - St Teresa's Hospice 01325 254321
 Durham - St Cuthbert's Hospice 0191 386 1170
 Gateshead - St Bede's Unit 0191 445 6435
 Hartlepool - Hartlepool and District Hospice 01429 855555
 Middlesbrough - Teesside Hospice Care Foundation 01642 816777
 Newcastle - Marie Curie Hospice 0191 219 1000
 Newcastle upon Tyne - St Oswald's Hospice 0191 285 0063
 Northumberland - North Northumberland Hospice 01665 606515
 Northumberland - Tynedale Community Hospice 01434 600388
 Stockton-on-Tees - Butterwick Hospice 01642 607742
 Sunderland - St Benedict's Hospice 0191 569 9191
 Tyne and Wear - St Clare's Hospice 0191 451 6378

Macmillan Network information and support service for the LD community
 Helpline: 01223 460 473
 Email: info@natnetpald.org.uk

National Network for Palliative Care for people with LD
 Tel: 0122 346 0473
 Email: LindaMcEnhill@natnetpald.org.uk

Learning Disabilities

Mental Health Foundation
 Tel: 0207 803 1100
www.mentalhealth.org.uk

Respond
 provides emotional support and counselling, for adults with LD families,
 carers and professionals
 Helpline: 0808 808 0700
www.respond.org.uk

Foundation for People with Learning Disabilities:
 Tel: 0207 803 1100
www.learningdisabilities.org.uk Email fpld@fpld.org.uk.

British Institute Of Learning Disabilities
 Tel: 01562 723 010
www.bild.org.uk Email enquiries@bild.org.uk

Down's Syndrome Association
 Helpline: 0845 230 0372
www.downs-syndrome.org.uk Email info@downs-syndrome.org.uk

Scottish Down's Syndrome Association
 Tel: 0131 313 4225.
 Email: info@dsscotland.org.uk

Mencap
 Tel: 0207 454 0454
www.mencap.org.uk Email information@mencap.org.uk

Mental Health

National Association for Mental Health (MIND)
 Helpline: 0845 766 0163
www.mind.org.uk Email contact@mind.org.uk

Physical Health

British Heart Foundation (BHF)
 Tel: 08450 708070
www.bhf.org.uk

The Neurological Alliance (epilepsy, multiple sclerosis, Parkinson's disease, motor neurone disease and other similar conditions)
 Tel: 0207 566 1540
www.neural.org.uk

The Stroke Association
 Tel: 0845 303 3100
www.stroke.org.uk

Policy

NHS Continuing Care regulations – NHS funded nursing care: Before October 2001, some people had to pay for their own nursing care. Now everyone in need, regardless of setting and means, is eligible for NHS - paid care from a registered nurse www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/IntegratedCare/NHSFundedNursingCare/fs/en

National Institute for Health and Clinical Excellence
 Tel: 0207 067 5800
www.nice.org.uk

Healthcare Commission
 Tel: 0207 448 9200
www.healthcarecommission.org.uk

Commission for Social Care Inspection (CSCI)
 Tel: 0207 979 2000
www.csci.org.uk

Cramlington 01670 707 900
 Darlington 01325 371 720
 North East Regional Office (Newcastle) 0191 233 3300
 North East Regional Registration Team (Newcastle) 0191 233 3310
 South Shields 0191 497 4220
 Stockton on Tees 01642 628 960

Useful documents

Various sites/documents on topics you may find useful and can download. Documents below can be accessed from the Department of Health website. Type in the title of the document in the search box on www.dh.gov.uk

- Our health, our care, our say: a new direction for community services - 2006
- National Service Framework for Renal Services Part 2 - 2005
- Supporting people with Long Term Conditions - 2005
- A toolkit for Older Peoples Champions - 2004
- Better Health in Old Age - 2004
- National Service Framework for Diabetes - 2005
- Independence Well Being and Choice - 2005
- Building on the Best: Choice, responsiveness and equity in the NHS: summary documents – 2004

NICE Supportive and Palliative Care Guidance
www.nice.org.uk/page.aspx?o=110006 - 2004
 Supportive and Palliative Care for advanced heart failure
www.heart.nhs.uk/scripts/default.asp?site_id=23&id=4668 -2004

Appendix - 1

Northumberland Tyne & Wear Learning Disabilities Programme

End of Life Care Sub Group

Jackie Sochocka

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Co Chair / End of Life Care Programme Manager, NHS North East.

Alan Cormack

Commissioner for Learning Disabilities, South Tyneside.

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Manager of the Northumberland physiotherapy service for people with learning disabilities, Northumberland Tyne & Wear NHS Trust.

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Macmillan Clinical Nurse Specialist Palliative Care Learning Disabilities, Northumberland Tyne & Wear NHS Trust.

Dr Heather Wilkinson

Senior Research Fellow, Centre for Research on Families and Relationships, University of Edinburgh.

Jackie Welsh

Modern Matron/Clinical Nurse Lead, Community Learning Disabilities Team, North Tyneside Primary Care Trust.

Appendix - 2

The End of Life Care Programme (EoLC) was launched in December 2003 by the Department of Health with the aim of improving care for people coming to the end of their lives, irrespective of their diagnosis. The programme seeks to provide greater choice for patients with regard to their place of care and place of death. The initiative also aims to reduce the number of emergency admissions to acute care for those who have expressed a wish to die at home and reduce the number of patients transferred from care homes to acute care within their last week of life.