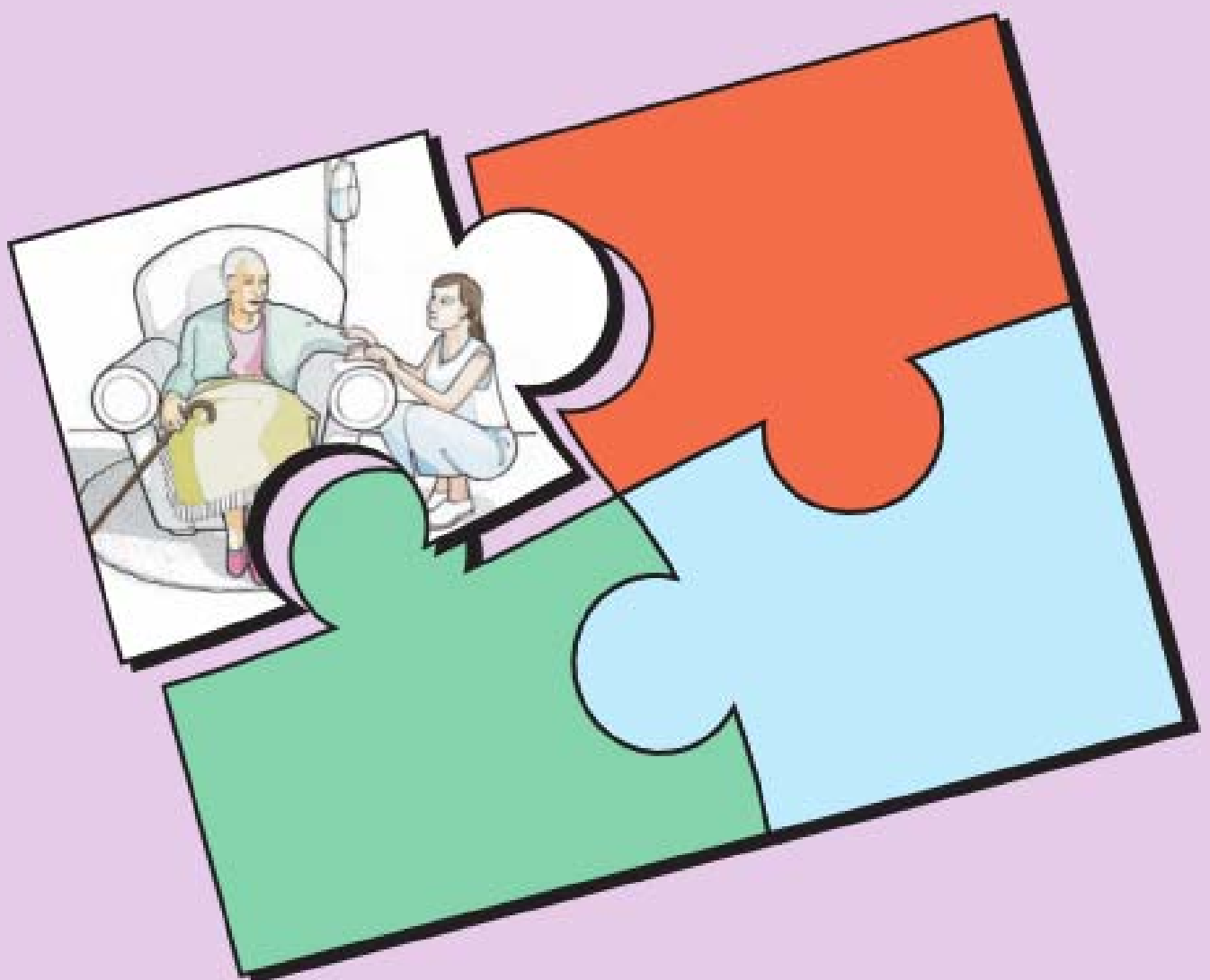


Living with an illness that I will die from

"The puzzle of palliative care"

(Phillip)



A Carers Guide

Introduction

People with a learning disability have a reduced ability to understand new or complex information, or to learn new skills (Department of Health 2001). They may struggle to cope independently with the everyday tasks of living that other people often take for granted. Some people may have problems communicating, and lack the full range of communication skills that are common to most other people. The help and support that individuals' need throughout their life may be varied, and sometimes additional help from other professions may be needed in the short or longer term. This could be the case when a person has been diagnosed as having a palliative illness.

This booklet has been designed to complement the four leaflets for people with a learning disability, and is divided up into sections accordingly, and may be freely photocopied.

1. Knowing when someone is ill

This section corresponds to leaflet 1. *Finding out...*

A palliative illness is one that cannot be cured (such as some cancers), but can be treated, and such treatments may prolong life, ease pain and discomfort, and help the person to cope with the illness. Common treatments include surgery, radiotherapy and chemotherapy. Palliative care and support helps people to cope with their illness, treatment and any resultant symptoms. This also includes support for the family and friends of the person who is ill. This leaflet is designed to help and support carers who have a relative who has a learning disability and a palliative condition. It offers information; clarifies terminology; presents some of the difficulties involved in this sensitive area of care; and provides some trigger questions for carers to think about at this difficult time.



"We know that people with a learning disability have poorer health than other people and are more likely to die younger" (MENCAP 2004), and some people with learning disabilities may not be able to tell you that they are unwell. Carers need to remain vigilant to spot changes that may indicate distress or ill health. Behavioural, physical, emotional and psychological changes (anything that is different from how the person usually is) often indicate distress and ill health and such changes that need attention include:

- Obvious lumps, swellings, pallor or discoloration
- Changes in weight and / or appetite
- Changes in toilet habits
- Breathing difficulties
- Change in usual social activities
- Physical changes e.g. looking unwell but not able to tell anyone
- Change in sleep patterns
- Skin changes
- A cough that will not go away
- Sores that don't heal
- Change in regular, known (or new) behaviours
- Clothes that no longer fit (either too big or too small)

This list does not include all changes, as specific illnesses present in particular ways, but recognising the changes are important since they could indicate ill health and the need for an appropriate professional assessment. You could talk to (and raise concerns with) your Doctor, Practice Nurse, Community Learning Disability Nurse, Social Worker, Day Service Officer, Specialist Nurse, District Nurse, Health Visitor, Key Worker, workers from MENCAP or other voluntary agencies.

2. What might happen next

This section corresponds to leaflets 2. *My questions...* and 3. *What next...*

The doctor might refer the person with a learning disability for tests, which may include x rays and scans; taking a biopsy (a small piece of the lump or tissue) to check it for disease; and blood tests. Following a full assessment and the diagnosis of a palliative condition, relatives and carers may need to consider how to inform and explain to the person about their illness and its effects. Breaking bad news can be difficult, but everyone has the right to know when they are seriously ill or diagnosed with a palliative illness. Making the decision to tell someone difficult news may be hard, as we try and protect loved ones from harm and sadness. However, people do need to know the truth and you may need to talk this through with other people to help you to find a way to do this.



a. Breaking bad news

Breaking any difficult news requires honesty, openness and should be delivered in a way that the person is likely to understand (for example using pictures, drawings and other techniques familiar to the person). Someone who knows the person with a learning disability well and who is known and trusted by the individual is usually the most appropriate person to deliver such information. Although we try and protect people from difficult issues, sometimes they surprise us with the way they receive and respond to the news, as John's story illustrates.

'John's story.'

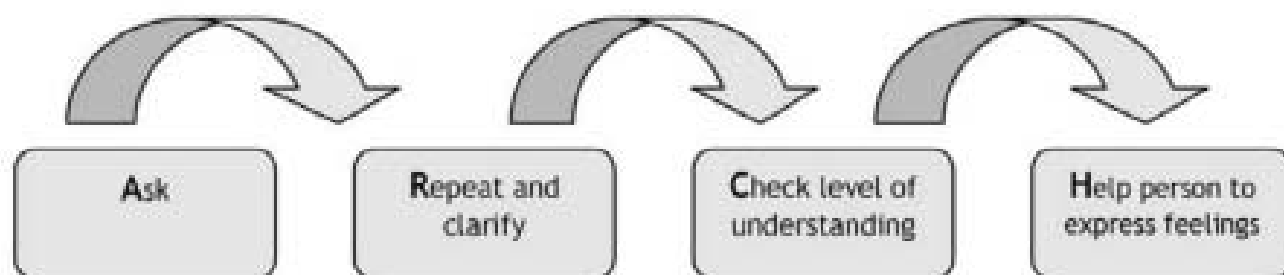
John was 38, had a learning disability, and lived at home with his parents. John was diagnosed with cancer seven months previously, and prognosis was poor. John accessed regular palliative care and support from a local Macmillan nurse and a community nurse. His mother contacted the Macmillan nurse and wanted her to visit as a matter of urgency. John's parents were both anxious that he was going to ask whether he might die from his condition, and didn't know what to say or how to say it.

When the Macmillan nurse duly arrived, his mother quickly escaped into the garden to tend to her washing whilst John's father went to the solitude of his garage. Eventually, John asked his Macmillan nurse if he was going to die soon. The Macmillan nurse explored with John what he already knew; clarified his understanding about his condition; and ultimately confirmed his worst fears. John then replied "Well don't tell my mum and dad, they'll never cope knowing this!"

¹ To ensure confidentiality and promote anonymity, this is a fictitious name and certain original details have been altered

This short case example shows how parents and carers often want to protect people with learning disabilities from knowing about serious illness and death. It also shows how much John had truly understood about his condition, and how he too wanted to protect the people he loved. Sometimes we make assumptions about people with a learning disability; about how much they understand and how strong, thoughtful and resourceful they really are. Responding to the person's own questions openly and honestly can minimise anxiety, reduce confusion and improve communication for all those involved.

Breaking difficult news is a process not an event, and may take many weeks to be fully conveyed to a person with a learning disability. The ARCH model below is a useful framework for breaking bad news to people with a learning disability (Read, 2006a).



Ask: Find out what the person already knows. Always use the person's name. Use simple questions to find out information. Ask what the person wants to know.

Repeat and clarify: Be prepared to go over information time and time again, in different ways (Books, photographs) and simplify if necessary. Carefully listen to the person and be guided by what they want and need.

Check level of understanding: Explore how much they know about the illness and what it means to them. Go back to previous stages if necessary. Be guided by the person.

Help the person to express feelings: Encourage expression of feelings, listen carefully and give support. Help the person to describe feelings, and explore what help they feel they might need next, future support options and choices and letting other people know (such as the Day Centre) if necessary.

When breaking bad news, always be guided by the person, use simple words, and use a consistent approach. Reinforce and affirm knowledge and answer questions as they arise. There may not be any definite answers to some of these questions, and you might need to seek advice from others and talk about it later. You might find hearing this news (and delivering it) very difficult, and need support. You might need someone else to help and support you to give the news, or to deliver it on your behalf with your continued support.



b. Words and phrases you might hear or use

Screening involves regular tests that pick up early signs (or cell changes), which may develop into cancer. Such tests include mammograms (to check breasts), cervical smear and testicular tests.

Tests such as **M.R.I.** (Magnetic Resonance Imaging), **C.A.T.** (Computer Axial Tomography) and ultrasounds are similar to an X ray, where rays are used to show changes in different parts of the body.

A **Biopsy** is when a small piece of tissue or part of a lump is removed and tested for cancer.

Cancer (or tumour, growth, carcinoma, mass, C.A.) is an illness that makes the cells in the body change. It can affect any part of the body.

Palliative care is usually associated with cancer but also includes other non-cancerous illnesses which cannot be cured, such as Alzheimer's disease, Dementia and Multiple Sclerosis. Palliative care is about making the last part of your life as good as it can be. It means getting help with symptoms, relieving your pain, and helping the person and their family and friends come to terms with what is happening.

Radiotherapy treatment uses rays on specific parts of the body where the cancer is. It is used to reduce the cancer.

Chemotherapy uses medicines (tablets or injections) to help reduce the cancer.

Hospices are places that offer specialist care and support for people who need palliative care. They are often more informal than a hospital, and those who work there are experts in caring for people with palliative conditions.

Respite care is offered at the hospice for those people with palliative care needs. This is a seven-day stay, usually planned, but can be accessed in an emergency. Respite care can also be offered through learning disability services, which may be a new or existing service for your relative.

Hospice at Home service is provided by the hospice offering terminal care to the person in their own home.

Macmillan Nurses, Marie Curie and Community and District Nurses are professional carers who help people to cope and live with their palliative condition in the home.

Terminal care is considered to be given during the last few days of a person's life.

The Liverpool Care Pathway (Ellershall & Wilkinson, 2003) is a document introduced and used by professional carers during the last few days of a person's life. This is in recognition that the person is dying and ensures that everything is in place to ensure an easeful death.

3. End of life issues

This section corresponds to leaflet 4. *Being prepared...*

a. Challenges

When death is close, coping with this situation is often difficult for the patient, family, friends and professional carers. Having a learning disability will complicate end of life issues for many reasons:

- Negative attitudes towards disability may make an initial diagnosis difficult and limit appropriate treatment options and care provision throughout the palliative care journey.
- Communication challenges often associated with people with a learning disability themselves e.g. recognising and expressing their own ill health and/ or discomfort from carers (who, perhaps, don't recognise ill health because it is masked by other symptoms such as epilepsy) and from professionals (who may not readily diagnosis a condition).
- Similarly, a person may present with a relatively simple and minor complaint (such as a headache), but when explored the actual pain or discomfort is really elsewhere (such as the stomach) but the person has difficulty explaining its exact whereabouts.
- An individual's cognitive ability i.e. their ability to think, reason and understand complex words and phrases, makes understanding of death difficult, fo all those involved.
- Explanation and clarification of illness and death is difficult, and one cannot always know exactly what the individual makes of his illness.
- Carers want to protect the person from the difficult reality of the illness, as illustrated in Roy's story.



²Roy's story

Roy was 53, and was married to Karen. They both had a learning disability, lived together locally in a flat and worked in sheltered employment. His wife Karen describes what happened when Roy became unwell: " Roy had had an agitated cough for a long time, and the cough got worse and worse. But he was a smoker as well, and that didn't help. He ended up going to the doctors. But a friend at work, where Roy worked every day, found a lump on his neck. It was a small lump, in his neck to start off with and then it gradually grew. It was in his neck, and I hadn't noticed it until my friend pointed it out. I took him up to the doctors, and he didn't know what it was. We kept going backwards and forwards because they didn't know what to do with him. They gave him some medicine to try and get the lump down, and took some blood to test. The medicine wasn't working, and the lump was still growing, so we went back to the doctors, and they sent him up to the hospital. This was in March. The hospital admitted Roy in March for the day at first, for a small operation, and they couldn't find anything wrong at first.

They operated on him, and when he felt well enough he came home that day in March. Then he went back into hospital in April, and at first they couldn't say what was wrong. The doctor then spoke to me and mum in a private room, and told us that Roy had cancer, and that he would probably only have six months to live".

Roy lost his voice due to his condition and the surgery, and subsequently had a tracheotomy and PEG tube fitted and for a long while was told very little about his condition. After much multi-disciplinary debate, care staff decided to tell him he was dying but only if he asked, which he eventually did just three weeks before he died. Roy used to frequently pull out his tracheotomy tube, and didn't really know what was wrong with him until close to his death.

Losing Roy was hard for Karen as she explains: "The hardest thing has been seeing Roy getting worse and worse, and not being able to do anything about it. Mum said the other night, if we could just have put our hands on him, to make him better, we would have done. I got through all this by myself, I believe in God and I go to church. My mum was very good, and it helped having someone to talk to. The staff were all good in the nursing home and the hospital."

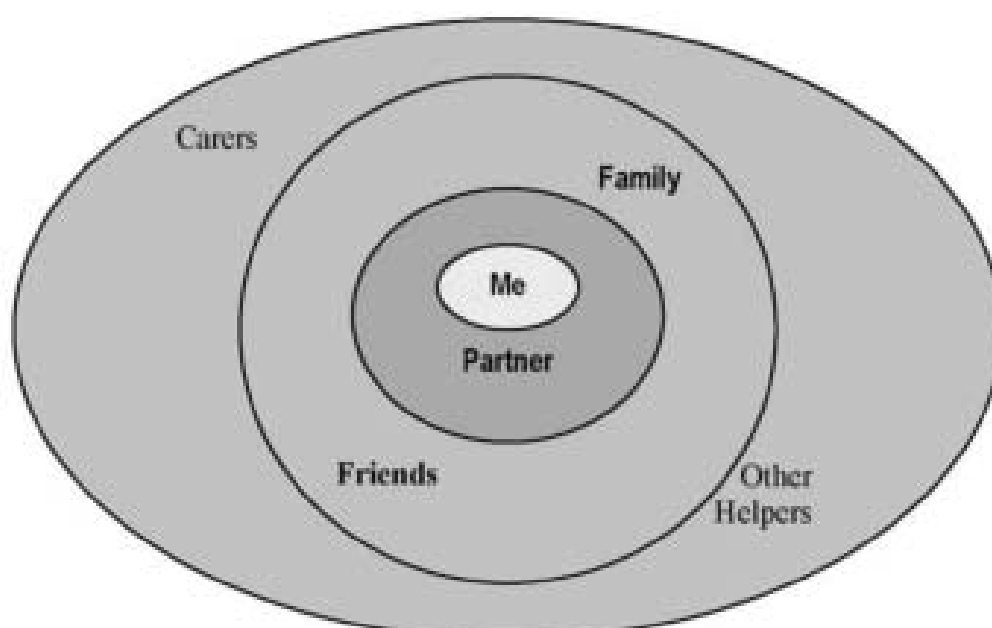
Roy's story illustrates some of the challenges involved when people with a learning disability develop a palliative illness. People tried to protect him from the reality of his illness by not explaining things to him and not actively involving him in the treatment process. Roy experienced multiple losses: he lost his voice both actually and

metaphorically; lost his independence; autonomy; familiarity and ultimately his life. Challenges included truth telling; pain and symptom management; communication; and dealing with the fear and anxieties of Roy and his wife. Roy frequently pulled out his tracheotomy tube, perhaps due to frustration, discomfort or fear of what was happening to him, we will never know precisely. During this time, support (for the patient, his immediate family and for the professional carers involved) became crucial.

b. Support

Counselling as support in the general palliative care context is usually sought from personal carers who may not be trained counsellors (Parkes et al 1996), but who may use counselling skills such as actively listening and 'being there' for the person. Consequently, people with a learning disability who are diagnosed with a palliative condition are likely to access support from familiar carers, therefore carers need to be prepared for this (Read, 2006b). People who care about a person often end up caring for them, and being there for the person; sharing emotional pain; hearing the tears and shedding tears are all part of the support process. As death approaches, people often want to try and make sense of life, and for some this might be a time of regret and/or celebration. Carers should make time to be with the dying person and help them to make peace with those around them. It may be a time of reminiscence; to reflect on past experiences, and a time to help the person to 'close the circle of friendships' (O'Kelly & O'Kelly, 2006), which are illustrated in Figure 1.

Figure 1: Closing the circle of friendships



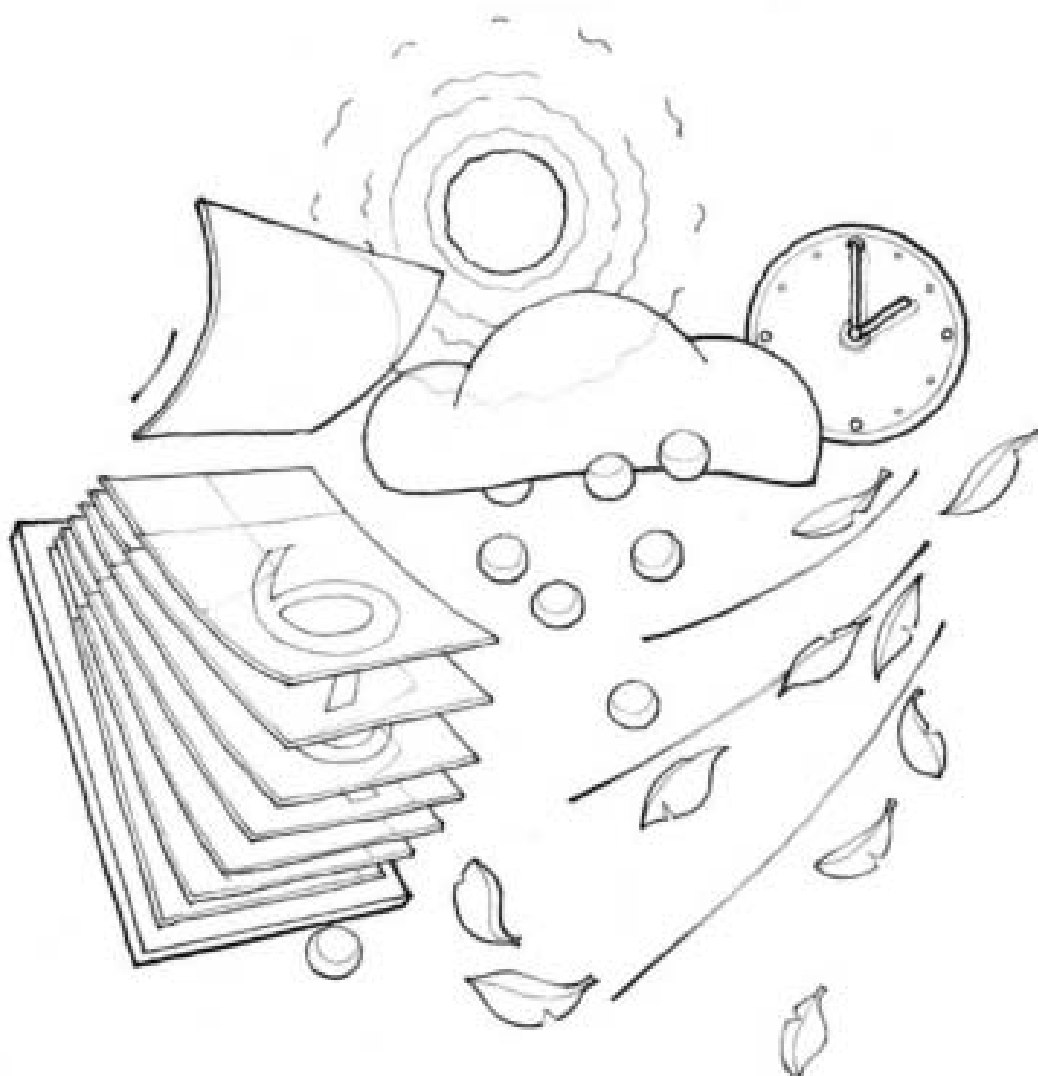
Death never occurs in a vacuum but in a social context, and all of those sharing the person's life will need variable support as death occurs and indeed afterwards. Try to keep friends (including other people with learning disabilities) informed and involved in what's happening, and encourage individuals to say their goodbyes. This might help the bereaved in accommodating their loss in the months and indeed years to come. You might also require the support of a professional counsellor (attached to the hospice or other professional service) to keep yourself emotionally safe and well.

For the carer, this can be a very exhausting time and emotionally draining. Offering continuous support to the person who is dying, other family members and friends can mean you don't leave yourself the space to get the support that you need as the primary carer. Remember, a healthy carer is an effective carer, and your support needs should not be ignored or overlooked. You may find some of the support you need from a particular family member, your local church, or professional carer, or through carer groups and organisations. Respite care for the person who is ill might be an option to consider. An occasional night out to visit a friend often helps to recharge emotional batteries.

c. Issues / questions you might want to consider

- Does the person know they are going to die?
- Does the person understand the concept of death?
- Do you feel comfortable enough to be able to talk with the person about death and dying? If not, who or what might help you?
- How much can the person be involved in their illness (for example when choosing treatment options)?
- Does the person have any religious or spiritual beliefs that they may need help with fulfilling?
- What does the person believe happens to them after they have died?
- Does the person understand the difference between burial and cremation?
- Does the person have any preferences as to preferring a funeral/ cremation/ service/ hymns etc? Is this information written down?

Dealing with death is never easy, but a healthy carer is an effective carer, so remember to look after your self. Where do you get your support from? In North Staffordshire you can get support from you local and national Mencap, your local hospice, carers organisations, the internet, Patient Advice and Liaison Services (PALS), advocacy services, Macmillan Cancer Support, doctors, religious leaders, and Causeway.



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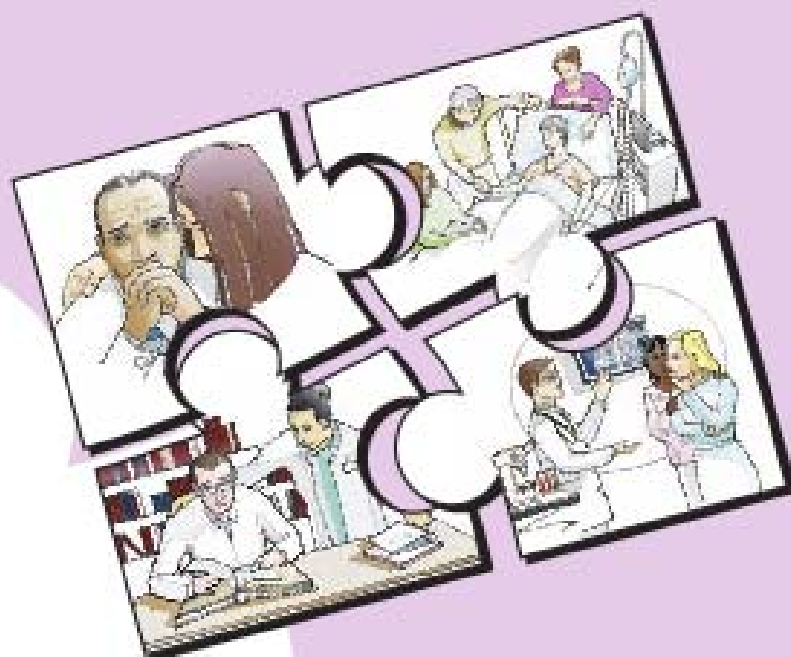
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This booklet has been designed to help those people who have relatives with a learning disability who have been diagnosed with an illness that they will die from. An illness that the Doctor cannot cure. They should be used in conjunction with the other supportive leaflets, for people with learning disabilities incorporating pictures and a booklet for professional carers. These leaflets should be used in conjunction with appropriate guidance and support from those caring for the individual.



P.C.L.D. - a multi-agency forum established to improve the quality of palliative care and support for people with learning disabilities in North Staffordshire.

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