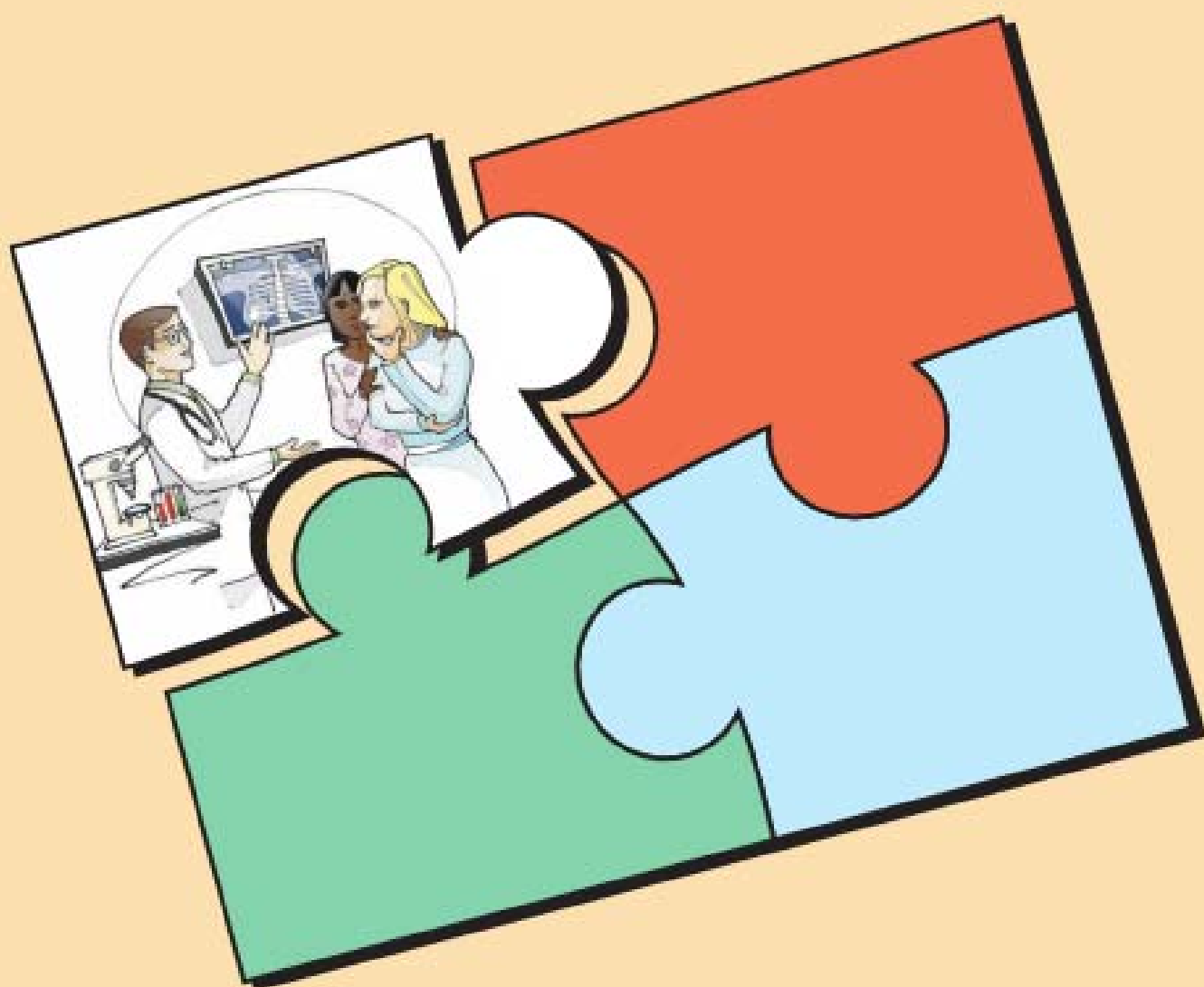


Living with an illness that I will die from

"The puzzle of palliative care"

(Phillip)



**A Guide for Professionals
Offering Palliative Care & Support**

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Acknowledgments

Dealing with death and dying is never easy, and developing this set of resources was a difficult task that spanned several years. These leaflets and booklets were developed by a multi-disciplinary group of people across health, educational and voluntary sectors in North Staffordshire; incorporating people with learning disabilities, parents of people with learning disabilities and regular consultation with local advocacy groups. Their time, commitment and dedication to the task was invaluable.

This tireless group worked for over three years with no identified funding, meeting at a local hospice when ever diaries allowed, beavering away in between meetings and other clinical activities, snatching working lunches to celebrate small successes as various parts drew to completion. We remain indebted to these people.

Thank you Phillip for coming up with the title of the resources, early on he recognised that palliative care is indeed a puzzle, where often people (or pieces) do not always fit nicely into allotted slots or resources.

Thank you also to the Douglas Macmillan Hospice, Blurton, Staffordshire for providing us with a regular, safe and comfortable space to work in and with access to lots of coffee. Finally, thank you to those individuals and organisations that kindly donated funds to support the publication of these resources. Without all of these people, the idea for these resources would never have come to fruition. Thank you.

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Introduction

"People with a learning disability who are dying are vulnerable adults on both counts: on account of their intellectual disability and their illness. Consequently they are in double jeopardy when it comes to having their needs met and their rights and entitlement to proper treatment and palliative health care honoured" (Read & Elliot, 2003: 5).

The emotional needs of people with learning disabilities are often neglected (Arthur, 2003), particularly in relation to death, dying and bereavement. In recognition of this, a series of resources have been developed in relation to palliative care and support for people with learning disabilities. These resources can be read independently and separately or in conjunction with each other for consistency of support. The series incorporates:

1. Four supportive leaflets that have been developed for people with learning disabilities incorporating drawings to promote understanding.
2. A booklet for personal carers.
3. This booklet, which has been designed specifically for those professionals who support people with a learning disability diagnosed with a palliative condition, from within a variety of caring contexts.

The aims of this booklet are to:

- Raise the profile of the support needed by people with a learning disability who are dying;
- Acknowledge the varied impact that both dying and death may generate;
- Promote understanding about the theoretical concepts around life limiting illness and death;
- Focus upon the practical approaches that may be used to support people with a learning disability diagnosed with a life limiting condition;
- Promote a consistency of palliative care and support to all people with learning disabilities regardless of where they live in North Staffordshire.

These resources were not developed to substitute education and training initiatives, but to complement these activities and will hopefully encourage communication between all people involved in

supporting individuals who have palliative care needs. This booklet has been developed and presented to correspond to the four leaflets for people with learning disabilities and the carers booklet. It should be useful to a range of professionals including: general nurses, Doctors, Community nurses (learning disability and palliative care), Agency workers, Hospice workers, Care providers, Residential community and support workers, Counsellors, Educators, Day centre workers, School nurses and Voluntary sector workers. They are also copyright free.

1. Knowing when someone is ill

This section corresponds to leaflet 1. *Finding out* and the carers booklet

a. Defining palliative care

Palliative care involves the active total care of patients and is defined as being *'an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and impeccable assessment of pain and other problems, physical, psychosocial and spiritual'* (World Health Organisation, 2003).

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.

b. Defining learning disability

People with a learning disability are described as *having a reduced ability to understand new or complex information, or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood and with a lasting effect on development* (DoH, 2004).

Subsequently, people with a learning disability people 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.

c. Communication

It is estimated that more than 50% of people with learning disabilities will have some form of communication impairments (Kerr et al 1996). Since communication is a two-way process, it is important to establish each individual's most effective way of communicating and to record this so that others are aware of it. To do this, professionals may need to ask the most significant people involved in that person's life. Once this is established, it is important to record and share it with all people involved in this person's care. When considering issues around consent, which are explored later in this booklet, it is important to assess individual communication skills to ensure the most effective and appropriate communication methods are used (DRC,2005). Speech therapists might be important to this process.

Consideration needs to be given to the various different and creative ways of communicating, and professionals need to adopt a creative approach when using different mediums in the communication process. Sometime, people with learning disabilities lack the appropriate, sophisticated language to express their ill health symptoms to those around them. Subsequently symptoms such as (for example) pain; difficulty in going to the toilet; not being able to eat properly; or not be able to sleep properly; may go unnoticed for some considerable time unless spotted by observant carers. Effective communication can involve using combinations of the following:

- Signs and symbols
- Pictures
- Sign Language (E.G. British Sign language)
- Simple language
- Accessible information
- Interpreters

d. Recognising ill health

"We know that people with a learning disability have poorer health than other people and are more likely to die younger" (MENCAP, 2004), and are likely to receive poor health care (Mencap, 2007). 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, which may need to be investigated. 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)
- Diagnostic overshadowing (when something else, such as challenging behaviours or even the learning disability itself, masks ill health)

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* *3. What next*, and the carers booklet.

a. Assessment

Assessment may be a common process throughout the lives of people with learning disabilities, but few assessments are focussed specifically on ill-health and associated needs, particularly in relation to palliative conditions. One of the biggest obstacles to accurate medical assessment is communication (Tuffrey-Wijne, 2003) and people with learning disabilities often have difficulties with reciprocal communication. Individuals may struggle to articulate their needs in a meaningful way, and may fail to recognise unfamiliar commands (during tests or procedures for example) without sensitive interpretations and clarifications by those closest to them.

One example of an assessment format that has been designed specifically for people with learning disability is the DisDat tool (Regnard et al, 2003). This resource is based around baseline behavioural observations of the patient, and can show subtle changes in condition over a period

of time. It is accompanied by comprehensive instructions to enable carers to use the tool effectively. Another simpler example is The 'Planning ahead to manage pain and distress confidently-checklist' (Brown et al 2005). This takes a qualitative and holistic approach to document the patient and carer experience of responses to (and management of) pain and distress and evaluates interventions to manage pain effectively for that particular individual. It is easy to complete and involves all those who know the patient well. Whilst such assessments may be crucial to the patient, they also contribute to the ongoing growth of paperwork associated with care delivery, and appropriate storage of easy access and retrieval of pertinent information is vital for the professional health care teams. However, much work needs to be done to evaluate the efficacy of any current assessment tool and practitioners need to work collaboratively to develop a range of tools in relation to this population.

Although diagnosis of a palliative condition may initially be difficult to ascertain for some individuals, once diagnosed, under the new GP contracts system (NHS 2007), palliative care registers within GP practices should enable health professionals to review such cases every four weeks (measurable under Quality Outcome Framework, NHS 2007).

b. Challenges to good palliative care and support

Some palliative care services (and those professionals working within them) may find working with people who are 'different' (such as people with learning disabilities or those who have mental health conditions) very challenging. Such challenges may be different depending on the context, experience and role of the professionals involved. Issues that may be problematic include:

- Communication challenges
- Ambivalent attitudes
- Knowledge and understanding of the professional caring for the patients
- Myths and preconceived ideas
- Fears (litigation, understanding, mis-diagnosis)
- Various professionals failing to work collaboratively
- Lack of resources (Assessment tools, communication aids, time, specialist people, books and other accessible information)
- History and continuity
- Lack of specific and explicit legislation and policy guidance
- Ethical tensions (consent to treatment, support, capacity)
- Disempowerment and marginalisation

It is useful to know about these potential challenges in order to anticipate and overcome them.

c. Defining associated terminology

There are a range of differing terminology related to palliative care, some of which include:

Screening involves regular tests that pick up early signs which may develop into cancer. Such tests include mammograms, 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, which can affect any part of the body.

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 and is usually planned. 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 with a priority in offering care in the terminal stages of the persons illness (and where available respite) 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 as is possible.

This list is not exhaustive and if any terminology is used that you do not understand then ask for clarification.

d. Diagnosis and prognosis

To diagnose a condition is to identify exactly what it is. In health care a diagnosis is the key to effective treatment options as professionals need to know exactly what condition(s) they are dealing with. Diagnosis may involve various tests or investigations (see previous section c) which are often important to allow access to appropriate services, treatments, practitioners and resources. Knowing what is wrong with a person is important to the patient, their family and carers. An accurate diagnosis may indicate a clear / potential prognosis (or expectation of outcome) and enables the individual, family and carers to plan accordingly. In the palliative care context, this might mean living with a palliative condition for many years or receiving a diagnosis which indicates that the illness is life limiting or that death is imminent. Once professionals have made a diagnosis, this information needs to be transferred to the patient, and when the patient has a learning disability, such translation of sensitive information may be difficult.

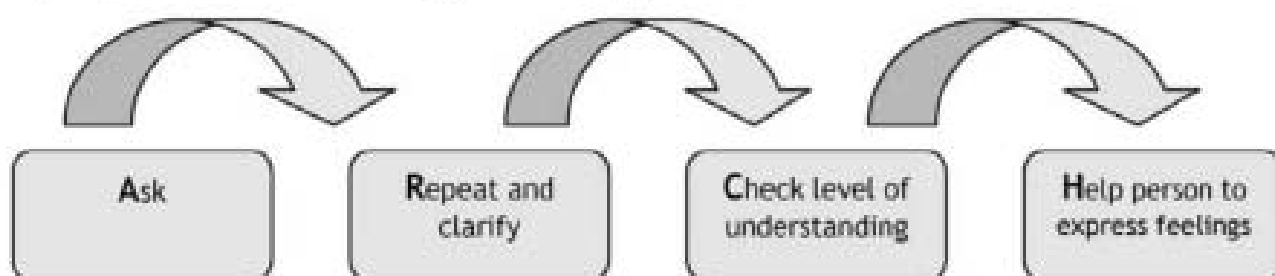
e. Breaking bad news

Receiving information that you have an illness that cannot be cured but may be treatable (or not) is bound to be difficult to hear and understand for many people. It may feel unreal and untrue. Individuals may not believe what professionals are telling them. If the person has difficulties in communication, the issues involved may be compounded. Subsequently, many people with learning disabilities die of their illness without ever knowing that they were so seriously ill. Sometimes this is because professionals do not feel that the individual is capable of understanding their diagnosis or impending death. Sometimes carers want to protect the person from the sadness of the associated and feared losses. Sometimes both personal and professional carers lack the appropriate skills to and knowledge to communicate such sensitive information in a meaningful way and don't feel comfortable with this task. Decisions about truth telling are not to be taken lightly and the

following pointers are offered to support these difficult decisions:

- Everyone has the right to know (and indeed not know) their diagnosis/ prognosis.
- The person who breaks difficult news should be considered carefully; preferably someone familiar with the patient should be there, in familiar surroundings, using a communication system appropriate to the individual's needs.
- Some patients may not ask about their condition, not because they do not want to know but because they may not be able to phrase the question well or feel that they can ask someone.
- People with a learning disability are reliant for so many people for so much. Professional carers should give people every opportunity to find out about their condition on a regular basis.
- Use simple, concrete language, that is jargon free, and be prepared to clarify and explain even the simplest of terms.
- Be prepared to be creative, using sign language, pictorial books or pictures where appropriate.

The ARCH model below is a useful framework for breaking bad news to people with a learning disability.



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.

(after Read, 2006)

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 the questions raised, and you might need to seek advice from others and talk about it later. Carers might find hearing this news (and delivering it) very difficult, and need support. Carers might need someone else to help and support them to give the news, or to deliver it on their behalf with their continued support. Carers need to anticipate the future (however potentially short) and encourage the person to plan for that time scale, identifying last wishes and preferred place of care / death wherever possible. In small community homes, carer's should also consider the needs of other people who live with the person who is ill as the end of life approaches, as they too need to understand what is happening to their friend.

3. Anticipating the next steps

This section should be read in conjunction with conjunction with leaflet 4. *Being prepared* and the carers booklet.

a. Who might be able to help

Help and support can be obtained from a number of generic and specialist palliative care providers, including the Doctor, Practice Nurse, Community Learning Disability Nurse, Social Worker, Day Service Officer, Specialist Nurse, District Nurse, Health Visitor, Key Worker, hospice professionals, or workers from MENCAP or other voluntary agencies. Additionally, family, friends and health facilitators, consultants, dieticians, respite services and the palliative care team can all contribute to effective end of life care.

b. Treatment options / Pain and symptom management

Pain and other symptoms that are distressing (such as nausea and vomiting, breathlessness and agitation) can sometimes be managed at home under the direction of the GP and/or hospice community nurse/ district nurses. A full holistic assessment is made looking at the person's physical, psychosocial, emotional and spiritual needs. For those with more complex needs, it may be suggested that a short stay at the hospice (to manage pain and other symptoms) may be required.

Useful assessments for measuring pain and distress in people with a learning disability include the DisDat tool (Regnard et al 2003) or the Abbey pain scale (Abbey 2000). Collaborative working and good reciprocal communication across the team is vital to both assessing and maintaining effective pain management.

c. Consent and capacity

Inability to gain consent or a lack of capacity are reasons cited by health professionals for not carrying out treatments for people who have learning disabilities (Djuretic et al, 1999). Any medical, therapeutic or caring intervention that involves the touching of another person requires consent. There are many ways in which a person can consent- and a number of different situations where these are appropriate; in some situations verbal consent is adequate-as is implied consent-such as having a blood test. However some treatments and interventions require a more formal explanation due to the possible risks associated with the procedure. The Mental Capacity Act (MCA, 2005) has provided useful information and is the appropriate tool to be used when seeking guidance around capacity and consent.

To summarise, there are 5 key principles which need to be followed:-

1. A presumption of capacity-every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
2. The right for individuals to be supported to make their own decisions-people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
3. That individuals must retain the right to make what might be seen as eccentric or unwise decisions;
4. Best interest-anything done for or on behalf of people without capacity must be in their best interests;
5. Least restrictive intervention-anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.
(DCA, 2005)

These principles should be considered in the complex decision making process at various points throughout the palliative care journey.

d. Promoting autonomy and choice

As the illness progresses, and more professionals become involved, the need to remain focused on the person who is ill remains paramount. As the illness progresses, and symptoms worsen, the ability to communicate may become compromised, particularly if you have a learning disability. Carers should work deliberately, creatively and flexibly to respect personal choices at this time (Jackson & Read, 2008), as illustrated very simply by John's story.

Case Study: John

John had bowel cancer and, towards the end of his life became particular about how much and what he ate. Instead of a large Sunday roast, he preferred a simple jam sandwich. Carer's respected this simple choice and preference.

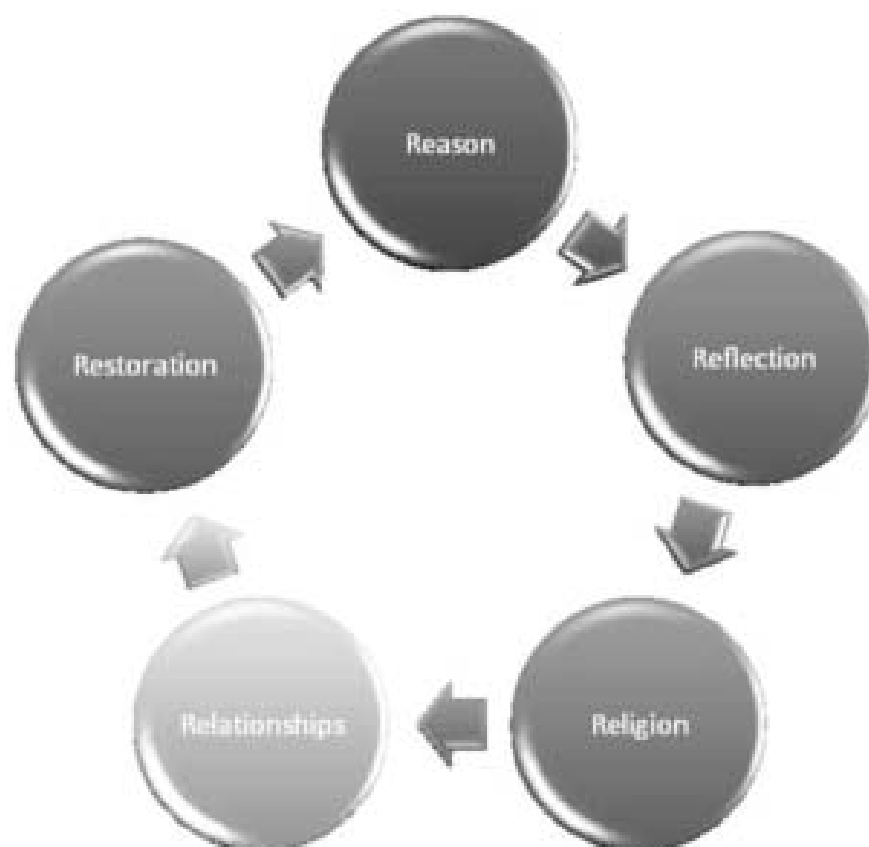
Refusal of care and treatment is a sensitive issue, and although a person may refuse treatment, and this choice is honoured, carer's still have responsibility to ensure that this is in the best interest of the person (see Section on consent).

For those people who do not or cannot communicate effectively at this time, professionals may need to seek help and advise through the multi-disciplinary team incorporating the person who is ill (where possible) family, advocates, familiar carers, associated health and social care professionals, and specialist palliative care workers. This circle of support is important to ensure a true understanding of the persons needs and wants is identified and recognised. Supporting people as they journey towards the end of life may be difficult for some carers, and support at this time needs to be acknowledged and is available through support groups, clinical supervision, counselling, peer support and other agencies. Preferred choices about end of life care should really have been ascertained earlier, and preferred choice about place of death honoured where possible and if known.

e. Spirituality

Spirituality is described by Vanier (1993) as the need of the whole person to be themselves, is perceived as being an indicative part of holistic palliative care, and a significant dimension of general human wellbeing (Narayanasamy, et al, 2002). Govier (2000) summarise the concept of spirituality as the five R's of spirituality, as illustrated in Figure One.

Figure one: Govier's five R's of spirituality (2000)



These five areas are a useful framework to assess spirituality generally, incorporating more broader issues than simply religion (Read, 2007). Assessing spiritual needs in the general population is often difficult to measure, and particularly so if the person has a learning disability. There are two resources that may be particularly useful when exploring the concept of spirituality with the person who has a learning disability from both a learning disability and carer perspective (see Hatton et al, 2004; Swinton & Powerie, 2004).

f. Care pathways

Care planning, and person-centred care, has been an integral part of learning disability care and support for many years, and has been developed to address specific areas of care such as community, forensic and mental health settings, and in response to complex needs, promoting health and palliative care settings (Gates, 2006). From a learning disability perspective, Read and Elliot (2006) have integrated essential lifestyle planning with palliative care to address the complexities of the duality of these conditions.

In recent years end of life care has become a focus for the Department of Health who have endorsed specific tools developed to improve end of life care including the Liverpool Care Pathway (LCP), the Gold Standards Framework (GSF) and the Preferred Priorities of Care

(previously Preferred Place of Care). The LCP was developed by Dr. John Ellershaw, Medical Director, Marie Curie Hospice, Liverpool, to transfer the hospice model of care into other settings, i.e. Hospital, nursing homes and the community. It is a multi-professional document which provides an evidence based framework for end of life care, which is now being trialed and integrated into other care contexts such as cardio-thoracic and intensive care settings.

The GSF was developed by Dr Keri Thomas, GP at Walsall, and is a practice-based system to improve the organisation of care for patients within the last 6-12 months of life. It identifies standards relating to key aspects of care: co-ordination of care, control of symptoms, continuity of care, continued learning, carer support and care of the dying. The pathway provides guidance on all aspects of care in the last 48-72 hours of life, which include comfort measures; anticipatory prescribing of medicines; discontinuation of inappropriate interventions; psychological and spiritual care and family support.

These tools act as a guide to health care professionals to ensure that patients with life limiting conditions can be offered choices regarding their care in the last year of life and in the terminal phase of their condition (i.e. the last few days of life). People with learning disabilities truly challenge all health care professionals involved in the application of these frameworks, since these tools are most effective when reciprocal communication is at its best. Therefore the successful application of such tools with people with learning disabilities will be dependent on collaborative approaches across multi-disciplinary (and between inter-disciplinary) teams to maximise communication and to meet individual priorities and choices of the individuals involved (Read et al, 2007; Jackson & Read, 2008).

g. Support

People who care about people often end up caring for people, and sometimes this is not always easy. Support may be needed for the person who is dying; for their family and friends in the home; and for the carers involved in offering continuous support. Asking for support may prove difficult for some carers, but sometimes one just needs an invitation to talk. Some professional carers may need formal support (such as clinical supervision), others may get their support from friends and family; whilst others seek peer support from work colleagues or professional counsellors. There is no prescription regarding what is the best for everyone, it is all about personal choices and preferences. Accessibility and confidentiality issues need to be considered when selecting any personal support system.

Conclusion

For many people diagnosed with a palliative condition the emphasis may be on control rather than cure, and such an illness is likely to impact upon the whole family, not just the patient. Appropriate care and support throughout this 'rocky' and potentially turbulent journey is vital. Collaborative approaches may be the key to effective palliative care and support, particularly if the patient has a learning disability (Jackson & Read, 2008). This booklet has been developed to help the range of professionals who may be involved in support people with a learning disability diagnosed with a palliative condition. Whether this condition be (for example) cancer, motor neurone disease, or cardiac disease, maintaining the patient at the centre of this care remains crucial, regardless of any social or learning disability.

This series of leaflets, developed in conjunction with the bereavement leaflets (BSLD, 2007, a,b,c), have been deliberately designed to complement each other and are designed in a similar format. It is sometimes difficult to provide effective, high quality palliative care, to people with a learning disability for many differing reasons. Although these resources may not provide all of the answers, they may provide guidance, options and support for the range of individuals involved. These resources were never intended to replace training and education around this somewhat complex area of care, but to complement any existing support.

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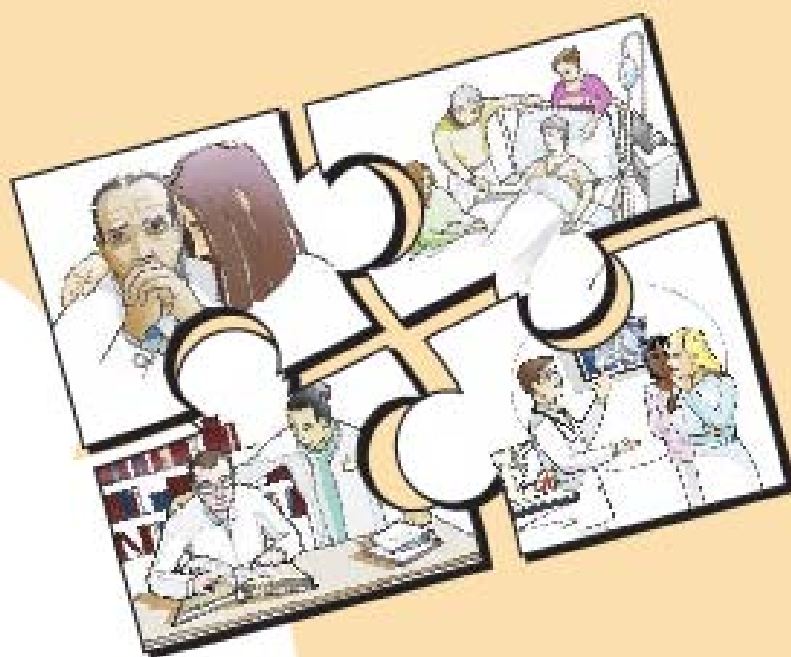
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This booklet has been designed to help those people who have relatives with a learning disability who have been diagnosed with an illness that they will die from. An illness that the Doctor cannot cure. They should be used in conjunction with the other 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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Illustrations designed by: creative.eye

2nd Edition 2010