

MANCHESTER LEARNING DISABILITY SERVICES

WHEN I DIE

END OF LIFE CARE PATHWAYS

July 2007

Manchester Learning Disability Services

End of Life Care-Pathways

Policy

PATHWAYS aim to allow families, staff teams and health care professionals to address dying with confidence, to help to honour each person's life and protect them from being diminished either as a consequence of their learning disability or of their final illness.

From Dying Matters – The Foundation for People with Learning Disabilities, 2005.

The Manchester Learning Disability Partnership Board encourages personal independence and people to work out and achieve what they want.

In doing this, The Partnership Board recognises four main concerns in relation to the end of life:

- Services must be committed to supporting people to **access all the appropriate mainstream services**. In considering the decisions about the end of life it is important to adhere to the principles of supporting access to, and supporting the staff in, mainstream services.
- It is important that the End of Life Pathway **includes stages before terminal illness**, including, ageing, and bereavement, advance directives including wills, funeral arrangements and wishes regarding organ donation. This is not only about cancer nor is it solely a palliative care issue.
- The pathway includes **support for people when they are bereaved** whether family members, co-tenants, friends, or staff.
- **Use of Person Centred approaches** is essential in all decisions and actions regarding the end of life and therefore all work in support of individuals will be in Person Centred Plans. Health aspects including links with mainstream medicine, health services, hospices and other services will be in personal Health Action Plans.

The point at which end of life issues are introduced into a person's plan will be a matter for sensitive judgement.

Approved for use in Manchester by
The Manchester Learning Disability Partnership Board
10th July, 2007

Notes on Pathways

I The General Pathway

1.1 Introduction

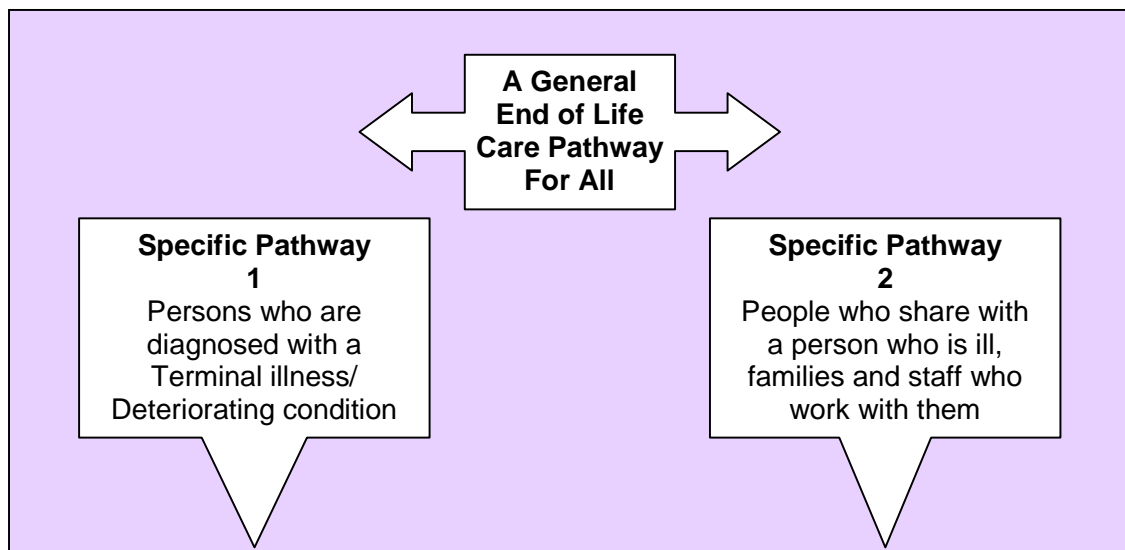
This is the Pathway which would apply to us all – if we were as well organised as we like the people who we support to be. It enables the affairs of people to be “in order” in advance and relies substantially on the *When I Die* booklet (copy included here pages 9 to 19).

Once diagnosed with a deteriorating or life threatening condition, specific pathway number one applies to the person concerned.

Pathway number two applies to the people who share accommodation with a person who is ill and/or for the staff in support.

Specific Pathways 1 and 2 build upon the prior wishes expressed in the General End of Life Care Pathway.

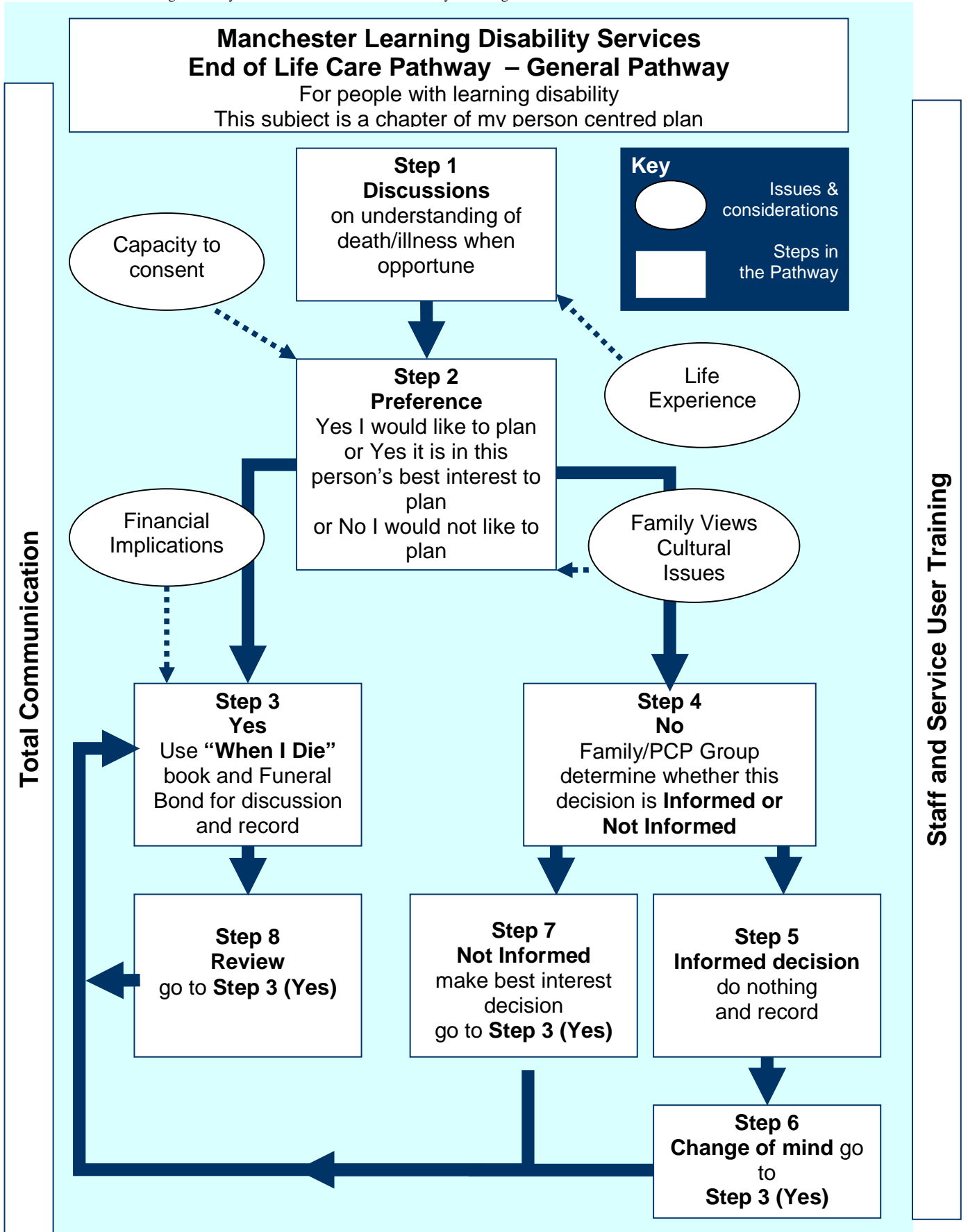
1.2 How the Pathways fit Together



1.3 This is a Part of My Person Centred Plan

As with all decision-making processes in services that support people with learning disability, end of life support will typically be discussed and decided upon as a part of their Person Centred Plan (PCP). The “*When I Die*” booklet, or an individually adapted version, can be used as a chapter in the person centred plan.

Training for end of life pathways should incorporate working in a person centred way.



2. The Steps in the General Pathway

2.1 Step 1 Discussion and understanding

For any decisions to be pertinent and helpful some prior discussion and understanding on end of life will be essential. Timing of these conversations needs to be thoughtful and sensitive, tentative chances may be taken and abandoned any number of times before it is right to proceed. It is not possible to make these kind of decisions in the absence of frankness. Openings arise in everyday life, such as a death in the family, within the local community or in a soap opera, which allow the topic to be raised and gradually built upon. This may lead to an informed decision or best interest decision to begin using the *When I Die* booklet or an informed refusal to talk about the issue.

Training and development should encourage the issue of dying as a proper matter for discussion and suggest ways that this might be achieved, for example, in discussion groups in day services or informally within the home. This is an area where some people with learning disability may be involved in training sessions with staff.

2.2 Step 2 Preferences

When the ground has been prepared the issue can be raised more formally at a review meeting and a person can state whether or not they would like to plan.

Training on capacity to make decisions and best interest decision making is relevant here.

2.3 Step 3 Yes I would like to Plan

When someone indicates that they are ready to start planning or it is decided in their best interest to start planning, it may be helpful to use the *When I Die* Booklet (included here at pages 9 to 19). This deals with the issues which we all have to face and gives people the opportunity to say what they would like in a way that suits them.

Remember that some people may not wish to discuss all aspects of *When I Die*. They may be willing to talk about the disposal of their personal belongings as a first step. It is important not to pressurise individuals and to allow them to engage in the process at their own pace.

The person centred planning group may wish to defer detailed discussion at this step and suggest that a named person, relative, friend or key worker attempt to work through the booklet with the person and report back, with them, at the next review meeting on the decisions which the person has made.

PCP training should incorporate the *When I Die* materials. Use of the booklet is, in itself, a training opportunity.

2.4 Step 4 No, I Would Not Like to Plan

The major concern here is to determine whether or not this is an informed decision.

Informed Decision Making - main points

IN LAW there is a presumption that people have the capacity to make decisions unless it can be demonstrated that they lack capacity. It is also clear that capacity to decide is not a once-for-all condition, there must be a test of capacity for each decision.

There are four tests of capacity:

1. Understanding the information about the decision.
2. Remembering the information.
3. Understanding the consequences of the decision or consequences of not deciding.
4. Making clear the decision to others.

Ref Mental Capacity Act 2005

It is not legal to conclude that a person has or has not capacity unless they have been given every available support in the process of decision-making. This includes: managing the flow of unpleasant information, use of non verbal methods, help from someone who knows the person really well, timing, making the information accessible.

A person may not be deemed to be without capacity solely on the ground that he or she may make what is seen as an unwise decision.

Previous inexperience in decision making may mean that more time has to be taken with some people in explanation and support in weighing options before deciding. Prior involvement in gathering health history in preparation for person centred planning and health action planning would be useful preparation.

Where there is no capacity to decide a best interest decision may be taken.

Best interests decision:

- Made by people who know the person well e.g. a PCP group
- Best decision for the person who lacks capacity – not for others
- Takes account of the person's known preferences

Decisions may be assisted or made by:

- attorneys, someone who has the legal right to make decisions on behalf a person (the donor). The Attorney is chosen by the person.
- deputies, someone chosen by the Court of Protection to make decisions for the person who lacks capacity
- and Court of Protection Order where there is a difficult decision or where there is disagreement.

Training on the Mental capacity Act, 2005 including capacity to make decisions, tests of capacity, best interest decision making are all relevant here.

2.5 Step 5 Informed Decision Not to Plan

In the event of a person deciding that they do not wish to plan, the person centred planning group should discuss whether this is an informed decision. If it is concluded that the decision not to plan is indeed informed, then services should support the person to do nothing at the present time. However, this does not rule out continuing discussion between review meetings and a change of mind, or a change of mind at a review discussion – see Step 6, below.

2.6 Step 6 Informed Decision Not to Plan – Change of Mind

It may well be that such a decision will, in time, be revised and the person may be supported to start at Step 3, (YES) above.

2.7 Step 7 Decision Not Informed – Best Interest Decision Making

In the event of a refusal to continue, which is not informed, the person's planning group may feel a responsibility to plan at least some of the basic steps on behalf of the person concerned. This should only be embarked upon if it is felt that the decision to refuse is not informed. A best interest discussion and decision may then be undertaken, following the process from Step 3 (YES).

3. Training Programme for People who use Services and their Staff

A key component of the Pathway is training for people who use services, families and staff who support them. Much of this may be undertaken jointly. Main topics include: how to use the Pathway; how to incorporate the Preferred Place of Care policy and moving on to a specific Pathway in the event of the diagnosis of a terminal or chronic condition; Mental Capacity.

4. Total Communication

This includes explanation of issues to people with learning difficulties and giving information in a way that is understandable to the person and which enables them to participate fully in the decisions affecting them. See note on page 8.

Total Communication

COMMUNICATION is a basic human right. It is the means by which we are valued by society and ourselves.

Explanation of issues to people with learning disabilities and giving information in a way that is understandable to the person can be difficult and it is important that a *Total Communication* approach is applied.

When skillfully applied, *Total Communication* involves flexible use of a number of ways including speech, gesture, drawing, writing, body language, facial expression, signing, objects of reference, photographs, symbols, vocalisation, intonation, access to modern technology and the use of communication books, maps and other environmental 'props' of enabling the person to participate fully in the decisions affecting them.

5. Keeping *When I Die* Planning in the Review System

When I Die planning is usually a part of the Person Centred Plan, it therefore follows that this will be subject to the normal review process and should be discussed, however briefly, when the PCP or Care Plan is discussed.

6. Recording

Decisions will be shown in the revised Person Centred Plan. It is important also to make a record of meetings and reasons why decisions have been made or options rejected. This may be done in the personal record.

MANCHESTER LEARNING DISABILITY SERVICES

Private and Confidential

When I Die

Photo















Optional

This person centred plan belongs to

Please treat this document with respect

July, 2007

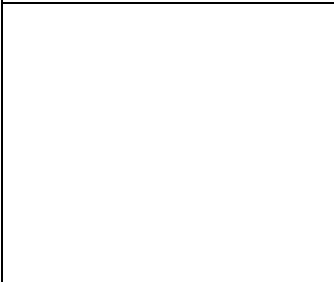
1.

ABOUT ME	
	My Name is:
	I like to be known as:
	I live at: Telephone 
	I am supported by: My Key Worker is: Telephone 
	My Next of Kin is: Telephone 
	My advocate is: Telephone 
	My Care Manager is Telephone 
	My Date of Birth
	My Ethnicity
   	My Religion is

This booklet is part of **My Person Centred Plan** and was made on
(date) see page 11 for changes made after that date.



Other People involved in the Discussion:



This was a "Best Interest Decision" Discussion

Yes



No



Circle Choice



I would like to be cared for in my own home if I am very ill

Yes



No




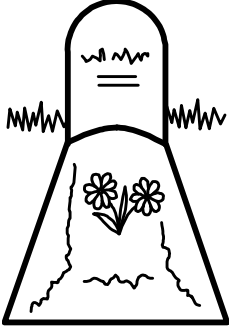
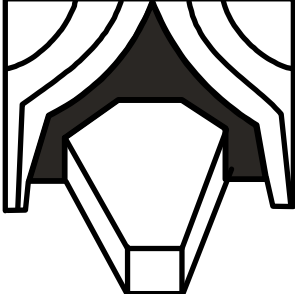
Circle Choice


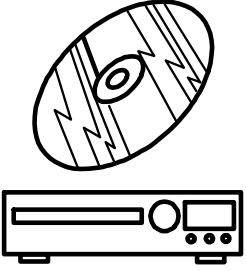

Please also see my *Preferred Place Of Care* booklet



Name of my Religious Contact Person

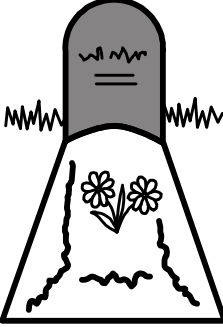



Address




Telephone: 

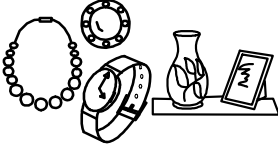
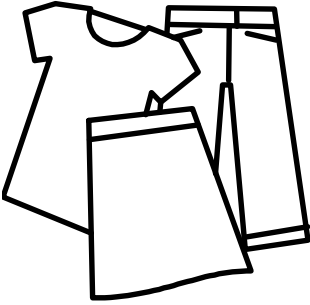
My Burial or Cremation	
<p>Burial</p> 	<p>I have decided that I would prefer to be buried.</p> <p>Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/></p> <p style="text-align: center;">Circle Choice</p>
	<p>I have a place in a family burial plot or I have purchased a plot</p> <p>Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/></p> <p style="text-align: center;">Circle answer</p>
	<p>If yes details</p> <p>If no I would like to be buried at:</p>
<p>Cremation</p> 	<p>Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/></p> <p>I have decided I would prefer to be cremated</p> <p style="text-align: center;">Circle Choice</p>
	<p>I would like this to take place at:</p>
	<p>I would like my ashes to be:</p>

About my Funeral Service											
Add picture	I would like my service to take place at										
	<p>I would like the service to be:</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center;">Formal</td> <td style="text-align: center;">Yes</td> <td style="text-align: center;"><input checked="" type="checkbox"/></td> <td style="text-align: center;">No</td> <td style="text-align: center;"><input checked="" type="checkbox"/></td> </tr> <tr> <td style="text-align: center;">Informal</td> <td style="text-align: center;">Yes</td> <td style="text-align: center;"><input checked="" type="checkbox"/></td> <td style="text-align: center;">No</td> <td style="text-align: center;"><input checked="" type="checkbox"/></td> </tr> </table> <p>Circle choice</p>	Formal	Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>	Informal	Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>
Formal	Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>							
Informal	Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>							
Add picture	<p>I would like (name) To officiate at the service</p> <p>Address</p> <p>Telephone </p>										
<p>Music</p> 	<p>I would like the following pieces of music to be played:</p> <ol style="list-style-type: none"> 1. 2. 3. 										
<p>Reading</p> 	<p>I would like the following to be read:</p> <ol style="list-style-type: none"> 1. 2. 										

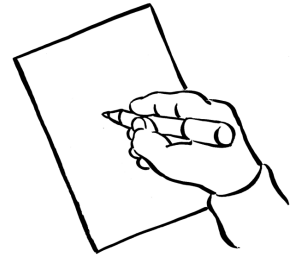
About my Funeral Service (Continued)	
	I would like these things to be placed in my coffin with me:
<p>flowers</p> 	<p>I would like flowers at my funeral</p> <p style="text-align: right;"> Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/> </p> <p style="text-align: right;">Circle Choice</p>
<p>Add picture</p>	<p>My favourite flowers are:</p>
<p>Donations</p> 	<p>Rather than flowers people may make donations</p> <p style="text-align: right;"> Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/> </p> <p style="text-align: right;">Circle choice</p>
<p>6.</p>	<p>I would like the donations to go to:</p>

About My Funeral	
I would like the place where I or my ashes are Buried to be marked with:	
	Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/> Circle Choice
In memory of... 	Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/> Circle Choice
Remembrance Book 	Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/> Circle Choice
Other  7.	For example A Tree Planted Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/> Circle Choice Description:

About My Will									
	<p>I have made a will:</p> <table style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="width: 25%; border: 1px solid black; padding: 5px;">Yes</td> <td style="width: 25%; border: 1px solid black; padding: 5px;"><input checked="" type="checkbox"/></td> <td style="width: 25%; border: 1px solid black; padding: 5px;">No</td> <td style="width: 25%; border: 1px solid black; padding: 5px;"><input checked="" type="checkbox"/></td> </tr> <tr> <td colspan="4" style="padding: 5px;">Circle One</td> </tr> </table> <p>My will is kept with (name)</p> <p>At address</p> <p>Telephone </p>	Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>	Circle One			
Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>						
Circle One									
My Funeral Plan									
<p>Funeral Plan</p> 	<p>I have a Funeral Plan</p> <table style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="width: 25%; border: 1px solid black; padding: 5px;">Yes</td> <td style="width: 25%; border: 1px solid black; padding: 5px;"><input checked="" type="checkbox"/></td> <td style="width: 25%; border: 1px solid black; padding: 5px;">No</td> <td style="width: 25%; border: 1px solid black; padding: 5px;"><input checked="" type="checkbox"/></td> </tr> <tr> <td colspan="4" style="padding: 5px;">Circle One</td> </tr> </table> <p>My funeral plan details are as follows:</p> <p>Name of Plan: _____</p> <p>Policy Number: _____</p> <p>Agency Address: _____</p> <p>Contact Number: _____</p>	Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>	Circle One			
Yes	<input checked="" type="checkbox"/>	No	<input checked="" type="checkbox"/>						
Circle One									
8.									

My wishes about my things	
	<p>I would like my things to go to:</p>
	<p>I would like my clothes to go to:</p>
<p>Advance Directive on the Acceptance or Refusal of Treatment</p>	<p>I would like you to help me:</p>
<p>Organ Donation</p>	<p>I would like to give parts of my body to help others when I die: Yes <input checked="" type="checkbox"/> No <input checked="" type="checkbox"/></p> <p style="text-align: right;">Circle one</p> <p>Details</p>
<p>9.</p>	

**Other Thoughts or Things
I Want to be Considered:**



7. Notes on the Use of the *When I Die* Booklet

7.1 General Working through this booklet is mostly self explanatory. Work on the book may be completed over a number of weeks or even months. The way in which the work is first broached is very important and needs to be done in a sensitive manner at an appropriate time. Many opportunities present themselves in day to day life which allows a start to be made in a natural way. Sometimes filling out the book will be well understood and informed by the person in others the gathering of information and decision making will be in *Best Interest* (see para. 2.4 above).

7.2 Preferred Place of Care It is important for people to look at this before the onset of a terminal or long-term debilitating illness so that their wishes are known. Such knowledge properly recorded will be useful in the final stages of life where there is concern about removal to hospital or hospice. It is plain that sometimes this will be necessary for short periods of treatment, pain relief and palliative care but clear instructions will enable the person to return to their own home. The details of this may be revisited if a terminal condition is diagnosed and a separate booklet may then be used (copy attached, at Page 27).

Todd, S. (2005) Surprised Endings: the dying of people with learning disabilities in residential services.

Todd found that from the moment the diagnosis of terminal illness was made known to staff, they almost instantly decided that service would continue to provide a home for the individual until their death. Staff saw this as a right for the individual, & also an opportunity for staff to express their caring concerns for the person.

7.3 Funeral Arrangements This section includes preferences for burial, cremation and the service which the person may wish to have a say in planning.

7.4 Funeral Bond A funeral plan or bond may be purchased from funeral firms or insurance companies and this enables pre payment for people who can afford this and who wish it, together with a measure of protection against inflation. *When I Die* book should state when a person has a bond and clearly give the location of the bond.

7.5 Wills People who are competent decision makers may wish to make a will. This should be encouraged and a record of where the document is located made in the *When I Die* booklet.

People who do not have capacity to make decisions cannot make a will and best interest wills do not appear to be a legal option.

However, based on their depth of knowledge, the key worker and family members may wish to help the person to decide on what happens to his or her personal possessions and clothes when they die. There is a section for this information.

7.6 Right to Accept or Refuse Treatment An autonomous adult with capacity to consent has the right to refuse treatment or to make it quite clear that they wish to receive treatment in all or any circumstances and to make an advance directive about this. An exception to this is where a person is detained under the Mental Health Act. Judging a person's capacity to make a decision is just that. It is not about whether, in the opinion of others, they are making the "right" decision, but whether they are making an informed decision.

Best interest decisions do not appear to be possible in advance of the onset of a terminal illness. However, treatment decisions for people who lack capacity and who are terminally ill will be taken in their best interest at that time.

IN THE case of R v Burke, July, 2004, the court concluded that where a patient lacks capacity and the treatment in question is life-prolonging treatment, that is providing benefit, such treatment should be provided unless the patient's life thus prolonged would, from their point of view be intolerable.

7.7 Donation of Organs

An adult with capacity to consent can make an advance directive about this. People with learning disability who have capacity may need support and guidance about this. Where this has been decided the person will need to carry an organ donation card.

There does not appear to be any way in which advance directives for adults who lack capacity can be made about this using the best interest principle.

Organ Donation legislation is currently under review (2007).

7.8 Review The person's PCP or Care Plan Review may modify decisions in which case it is important to update the *When I Die* booklet. The dates of changes must also be identified in the review section (page 11 of *When I Die*).

Manchester End of Life Care Pathway – Specific Pathway 1

For use in Progressive or Deteriorating Illness

Such as: dementia, stroke, multiple sclerosis, Parkinson’s disease, cancer

This Subject is a Chapter of My Person Centred Plan and follows on from the General Pathway

Key



Issues & considerations



Steps in the Pathway

Total Communication

Capacity to consent

Support Plan
Staffing
Equipment & Adaptation to the Place of Care.
Co-tenants
Guidelines.
Staff Support.
On-Call Support.

Step 1
Suspicion of condition

Step 2
Refer to GP comprehensive investigations

Step 3
Diagnosis or health problem identified

Step 4
Convene Clinical Team determine Treatment Plan

Step 5
Predict Likely Progression if possible

Step 6
Identify Wishes incl. Preferred Place of Care

Step 7
Determine Support Needed Including Plan for Sudden Deterioration

Keep Commissioners Informed throughout the process

Treatment Plan

Roles
GP/ Lead Clinician
Clinical Team
CLDT
Key worker
Care Manager
Family

Family Views
Cultural Issues

How is move from Preferred Place Of Care to Hospice or Hospital to be triggered ?

Staff and Service User Training

8. The Steps in Specific Pathway 1

The steps in this Pathway are intended as a Guide to be followed when a serious life threatening condition or long-term illness is suspected or diagnosed.

8.1 Step 1 Suspicion of Condition

People with a learning disability may be more at risk from illness than other people. They may be more prone to chest infections, respiratory failure, have eating and drinking difficulties; specific syndromes may be associated with particular health issues. Health action plans will highlight these risks and health screening will perhaps, identify illness at an early stage.

Staff support is, increasingly, being organised in a way that permits better continuity and consistency of care. People who provide personal support know what is usual for individuals and are best placed to spot the onset of changes and warning signs.

8.2 Step 2 Referral to the GP

If referral to the General Practitioner is necessary it is vital that the person is supported by someone who knows him or her well and who has all the relevant information with them. Intensive investigations and assessment will usually follow although it may be that a level of persistence is necessary to achieve this if the person is unable to communicate or does not obviously appear to be in pain. Other appointments may follow leading to diagnosis.

8.3 Step 3 Diagnosis or Problem Recognised

Diagnosis of a life threatening or progressive illness requires that plans are in place to ensure not only delivery of the person's wishes and clinical interventions but also to secure best support in the person's home. This could be their own tenancy, the family home or in a group home.

8.4 Convene Clinical Team - The Treatment Plan

The Care Manager or lead clinician has a responsibility to call together all primary health care professionals involved with others who may have a role for example McMillan services, together with a family member or key worker from the main support agency. At this point a *Case Coordinator* should be selected by the team.

The team will produce and regularly revise a Treatment Plan, which is a part of the Health Action Plan, including consideration of any advance directives which may be in place.

The Clinical Team will consider application for continuing care status and funding from the PCT. This may enable additional resources for health care, such as temporary increases in staff support to allow the person to be cared for in their own home.

The Link to the Health Action Plan (HAP).

SINCE, 2005 it has been government policy that a person with a learning disability be offered a Health Action Plan.

Even though the health issues are complex and so the background information and history may be huge. The HAP itself is a simple summary statement of the following:

- The health need,
- how it is to be met,
- who is responsible for meeting the need,
- who is responsible for the support necessary for this to happen
- completion dates

Although at the end of life individual components of the HAP may be subject of long reports, guidelines, prescriptions or other professional communication, the HAP format should continue to be used as the overall summary of who does what and when.

Eg:

No	Identified Need	Treatment & Support Needed	Person Responsible	By when
1				
2				
etc				

8.5 Step 5 Predict the Likely Progression

The course of any illness will vary tremendously from person to person, nevertheless it is impossible to make decisions about the future without some judgment of what the future might hold. Knowing about the illness is as essential to those giving day to day personal and social support as it is for the health team.

8.6 Step 6 Identify Personal Wishes including the Preferred Place of Care

Many illnesses require periods of inpatient or outpatient care in hospital or hospice.

It does not follow that people with a learning disability have to stay in a medical or clinical environment for any longer than necessary. Following the Preferred Place of Care booklet will ensure that this does not happen. (Copy enclosed at page 27)

8.7 Step 7 Support Needed – The Support Plan

A plan for the person’s support at home can be constructed in the light of the clinical evidence and the wishes of the person.

This will include:

- staffing arrangements
- adequate information,
- understanding and support for other members of shared tenancies,
- equipment, adaptations to the property,
- guidelines to staff on personal and social care, management of pain and dealing with health care plans
- dealing with health care professionals in the home.
- loss, bereavement and grieving
- emotional needs including consideration of if, and when, to inform the person that they are dying
- well-being
- spiritual needs
- communication needs
- occupational needs
- on-call management support for staff

Guidance on what to do in the event of deterioration, whether sudden or gradual, needs to be in place. Reliable on-call arrangements in the management support plan will ensure that families and staff are supported, in the event of deterioration, to make the right decision and reinforce that it is permissible for someone to die in their own home.

Details on the circumstances under which any move from the preferred place of care to a hospice or hospital will be included in the treatment plan. There have been examples where emergency services have removed this choice from a dying person simply because the support for staff decision-making was not in place.

Capacity to consent

CONSENT is the voluntary and continuing permission of a patient to receive a particular treatment.

Most people who have life threatening conditions or illness want the best treatment possible. The majority of people are willing to endure the pain and discomfort of treatment in the short term to obtain cure, remission or reduction of symptoms. It cannot be assumed that people with learning disabilities are any different in this respect. Apparent refusal of treatment or anxious or aggressive behaviour in the face of treatment options should not be automatically interpreted as refusal, without applying rigorously, the tests of capacity - see para. 2.4 above.

Bereavement

BEREAVEMENT is the reaction to the loss of a close relationship. It is possible for people to have a bereavement reaction to news of their own imminent death. People who live in groups and staffed settings may feel bereaved by, for example, the death of a person such as a co-tenant, friend or co-service user at the day centre or a member of staff.

Bereavement has several stages, all or some of which may be felt and have to be worked through:

- **Shock** - physical collapse, numbness, apathy, bewilderment and disorientation
- **Denial** - disbelief
- **Searching** - yearning for the person including visualizing the person, mistaking others for the person.
- **Grief** - realization that the person is not coming back. This may involve anger, anxiety, crying
- **Acceptance** - resolution of grief and adjustment to life without the person

People may work back and forward through the stages. People with learning disability may be able to tell their support staff about how they are feeling others may also show grief in behavioural ways such as loss of sleep, changes in sleep patterns, changes in appetite, uncharacteristic incontinence, changes in behaviour which challenges their regular support staff.

Referral may be needed to a member of the Community Learning Disability Team if people appear to be having particular or prolonged difficulties in any particular phase of the bereavement process or where the death is unexpected, sudden, or where there is a feeling of injustice about the death.

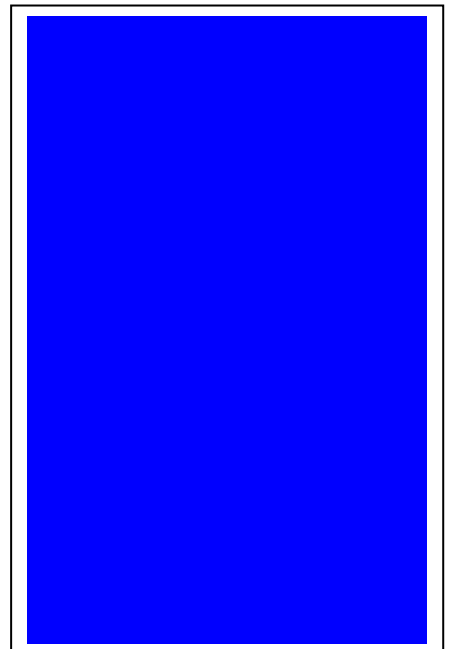
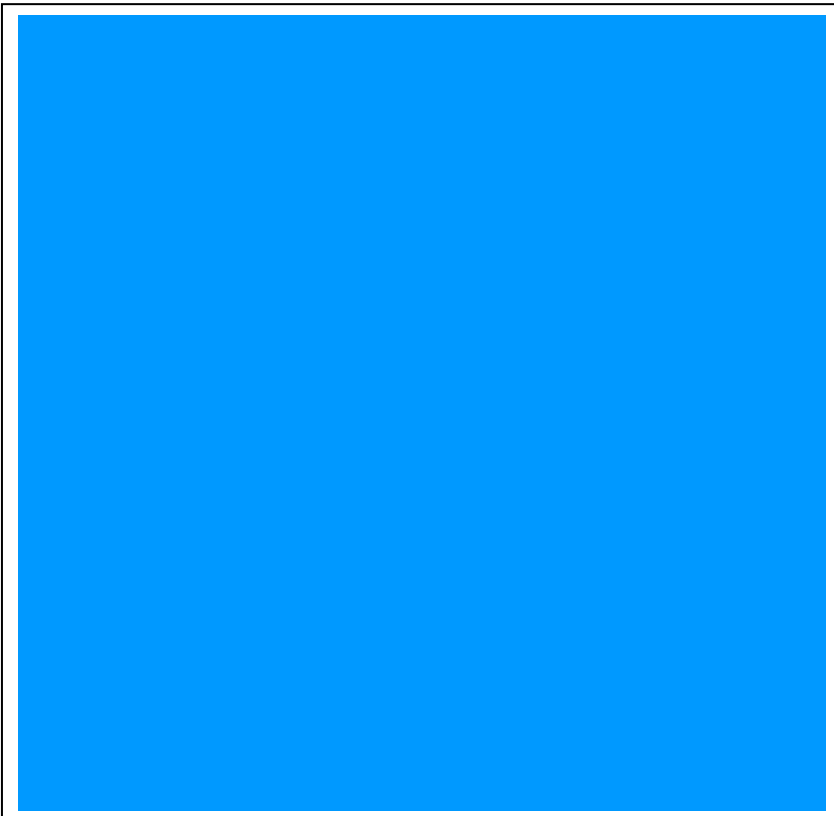
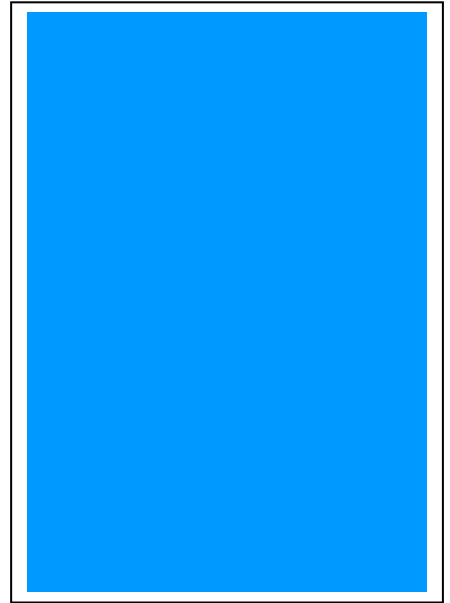
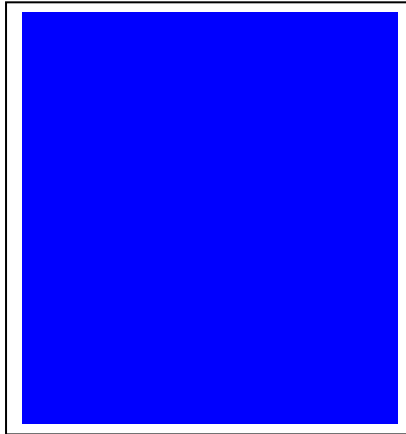
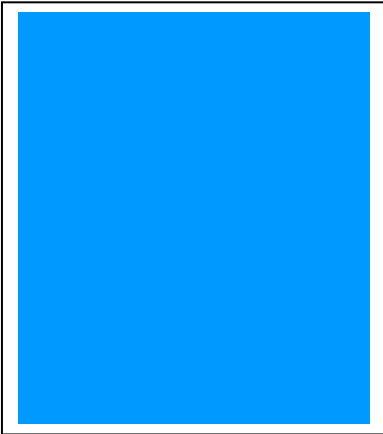
People who are bereaved may need help with coping with problems of every-day life, to leave their home, engage in every-day activities, interfere with work or return to work or day centre and/or usual leisure pursuits.

There is a need to be aware of different religious and cultural needs at all stages of the support given to people suffering bereavement and loss.

9. Use of the Preferred Place of Care Booklet

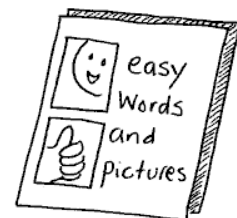
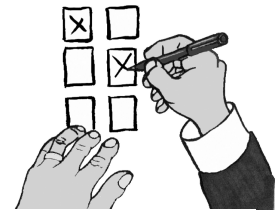
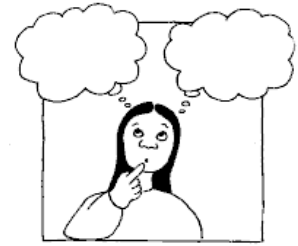
When it appears that The Clinical Team has to decide that a move to hospital or hospice is necessary the Preferred Place of Care plan enables choice, ensures that staff working in health settings have the information needed to give effective treatment and care. Someone who knows the person well will assist them to fill out the plan or do this in their best interest. The booklet is self explanatory and is attached at pages 27 to 42. Note: When admission to hospital or hospice is agreed, the hospital admission information pack should accompany the person. This is in addition to any other paper work required at the time.

Preferred Place of Care (Accessible Version)



Preferred Place of Care

- It's important that people have a choice of where they receive care and support when very ill.
- This plan is a record of your choices regarding the place of care and support you would like to be if you become terminally ill.
- This plan has sections that will be completed by you and maybe the people who support you and sections that will be completed by professionally paid staff.
- Within the plan you are asked for details about your home. This will help the people helping you to complete this plan to have a good picture of your current life.
- Within the plan it will detail how you communicate which will help others to support you better.
- Page 9 of the plan is a record of any changes to your care and support for example if you are referred to a different specialist or have to spend some time in hospital.
- Should you need any help in completing any parts of the plan please ask your carer for help



Preferred Place of Care - About Me



Name:

Male Female (circle one)

Address:.....

.....

.....Post Code.....

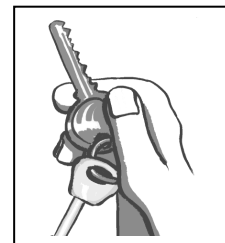
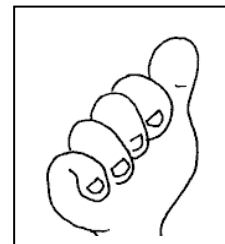
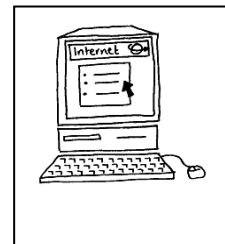
Tel:  Mobile: 

NHS No.....Date of Birth




Confidentiality

- Your information may be kept on our computer.
- We will also keep written records to check your care and support.
- The personal information you give use is confidential.
- Your information will only be released to other people with your permission.
- our information will be held in safe place and will be for people who need to know about it.




Information

My Next of Kin/Main Carer.....

.....Tel. No 




My Doctor.....

.....Tel. No 



My District Nurse.....

.....Tel. No 



My Specialist Nurse/AHP/LD.....

.....Tel. No 



My Primary Care Trust contract address.....



.....

Tel. No 

My Local Hospital address

.....

Tel. No 

Other.....

This is my present living situation

House

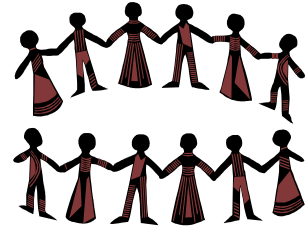
Access

Sharing

Support




My support networks available from family, friends or others:

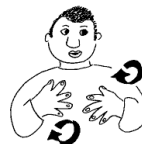
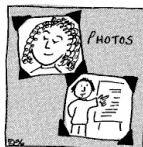


Needs of my family/friend/co-tenants or support staff needs



Marital Status (tick box)	Dependants 	Main carer(s) (tick box)
Single <input type="checkbox"/>		Family <input type="checkbox"/>
Married <input type="checkbox"/>		Friend <input type="checkbox"/>
Living with partner <input type="checkbox"/>		Support Staff <input type="checkbox"/>
Widowed <input type="checkbox"/>		
Divorced <input type="checkbox"/>		
Separated <input type="checkbox"/>		

Communication:



I communicate by using:	Tick	Other Comments	
1. Speech			
2. Pictures, photos, symbols.			
3. Signing system (i.e. Makaton, BSL, etc).			
4. Own gestures.			
5. Action, behaviour etc.			
6. Noises, vocalisations etc			
7. Objects (e.g. bringing coat to say I want to go out).			
8. Uses Information Technology equipment.			
	Circle	Other Comments	
I understand words that are spoken to me	Yes	No	
I have a communication Dictionary or Passport to aid my communication	Yes	No	
I can read?	Yes	No	
I have a Speech & Language Therapist	Yes	No	

Support and Care Plan

- While I have been ill this is what has been happening to me:



How my family, friends or support staff think I am affected by my illness:



It is important to me (in relation to my illness, treatment, care, support) that:



What is important for me (Family, friends or support staff views, what needs to be in place to keep me healthy & safe?)



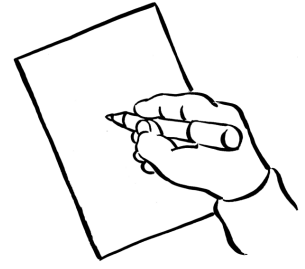
Place of Care – My Choices



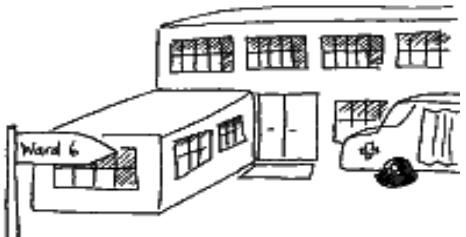
My Family, friends or support staff view





Additional notes or considerations.



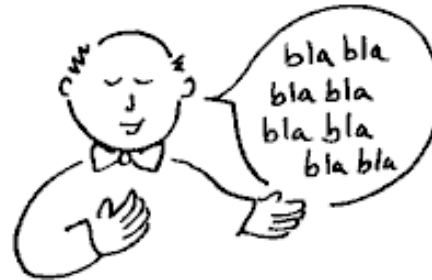
Complete the table below as soon as a person is diagnosed. When the person uses new or different services, update the Care Sheet and ensure that the document goes with the person. (The person, carer, support staff or Health Care Professional can complete this page)

	Services available locally (please tick)		Services currently Being accessed (please tick)		Date referred	Date of admission/attendance/ receipt of services and any comments	Date discharged
	Yes ✓	No ✓	Yes ✓	No ✓			
Care home							
Hospital <ul style="list-style-type: none"> • In-patient • Out-patient 							
Hospice <ul style="list-style-type: none"> • In-person • At home • Day Care • Respite Care 							
<ul style="list-style-type: none"> • Social Services/Care Agencies • Social worker • Specialist Palliative Care Social Worker 							

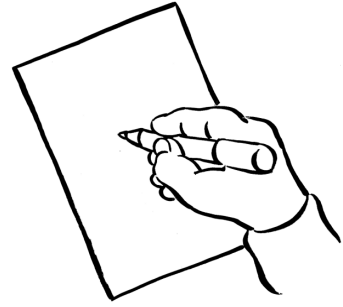
	Services available locally (please tick)		Services currently Being accessed (please tick)		Date referred	Date of admission/attendance/ receipt of services	Date discharged
	Yes ✓	No ✓	Yes ✓	No ✓			
District Nurse availability (hr available...) • Daytime..... • Evening..... • 24 hr.....							
Marie Curie service • Daytime..... • Evening..... • 24 hr.....							
Specialist Nurse – please specify: e.g. Community Matrons, Macmillan/ Admiral Nurse, other specialist nurses or professionals. • Daytime..... • Evening..... • 24 hr.....							
GP Name.....							

	Services available locally (please tick)		Services currently Being accessed (please tick)		Date referred	Date of admission/attendance/ receipt of services	Date discharged
	Yes ✓	No ✓	Yes ✓	No ✓			
Allied Health Professionals <ul style="list-style-type: none"> • Physiotherapy • Occupational Therapist • Dietician • Podiatrist/Chiropodist • Speech & Language Specialist 							
Support System e.g. Religious contact person/PALS, Counsellors (please specify)							
Access to other support services e.g. Complementary Services, other specialist services, befriending schemes, self-help groups, religious groups							
Comments (e.g. if services are available and are easy to get to)							

We would like to hear any comments you have on the provision of the care and support you are receiving, and any services that are available.



My Notes



Manchester End of Life Care Pathway – Specific Pathway 2
For Co-tenants, Friends & Staff of persons with progressive or deteriorating illness
This Subject Is A Chapter Of Person Centred Plans of those concerned and used in conjunction with Specific Pathway 1

Key

- Issues & considerations
- Steps in the Pathway

Step 1
Comprehensive assessment and diagnosis

Step 2
Likely progression

Step 3
Effects on others

Step 4
Determine how people to be supported

Step 5
Update PCP(s) and HAP(s)

Step 6
Conduct a review

Capacity to consent

Ill Person

Family Views
Cultural Issues

Co-tenants
Friends
Staff

Co-tenant/ Staff guidelines

- Understanding the Condition
- Counselling
- Adaptations
- Accommodation issues
- Preparation for funeral
- bereavement
- On-call support

Keep Commissioners Informed throughout the process

Total Communication

Staff and Service User Training

10. Steps in Specific Pathway 2 – Support for Friends, Family and Staff

10.1 Step 1 Diagnosis

When diagnosis is made family members, managers, staff and team members will, naturally, be occupied with providing a Treatment Plan and a Support Plan for the ill person. It would be understandable, therefore, that the needs of others who share with, and support, the ill person are relegated to second place. It may be that early notice of the condition should be shared openly, with the agreement of the person or in their best interest, so that the effects of the illness do not impact suddenly.

10.2 Step 2 Likely Progression

Depending on the diagnosis it may be possible for a judgment to be made about the likely progression of the condition so that plans for the family, co-tenants and staff may be put in place.

10.3 Step 3 Effects on Others

Sharing a home with someone who has a deteriorating illness will be difficult and individuals will need support and knowledge to help them understand the person's illness, their changing needs and their behaviours.

Judging the effect that a deteriorating illness will have is not easy and it will need considerable discussion in families, staff teams and with co-tenants in order to decide how best to handle the situation.

Families, staff and co-tenants will need support and preparation for the death of someone who they support/share with throughout the bereavement period which follows. This may include referral to mainstream bereavement counseling services, support groups etc.

Todd, S. (2005) Surprised Endings: the dying of people with learning disabilities in residential services.

On support needs of staff Todd reports:

Staff were generally told to be "professional" (following death of client). For many staff groups, the aftermath of the lack of support they had received during this period was bitterness or resentment.

One of the most difficult issues faced by staff was whether the client should be informed about their dying status. Their condition was hidden from them by staff, which took its toll on staff and only added to their emotional turmoil.

10.4 Step 4 Plan Determine How People are to be Supported

A support plan for the person concerned, his or her family, friends and staff will be drawn up by the multidisciplinary team and will be assisted by the contents of the treatment plan. This might include:

- Understanding the condition so that impact upon the lives of others may be judged.
- Preparation for bereavement
- Preparation for funeral
- The support needed by co-tenants
- The support needed by staff
- The support needed by family members
- Consideration of health, social, emotional and spiritual needs of co-tenants, family members and staff
- Possibility of temporarily moving out or taking a break/holiday
- Counseling
- On call management support
- Possible additional staffing resources for temporary periods

Training Needs include: understanding specific conditions for example dementia, dysphagia, the need for continuing and additional support, loss, bereavement, grief

10.5 Step 5 Updating Health Action Plans and Person Centred Plans

The documentation at this time will include updating the person centered plans and health action plans of the person and his or her near friends and co-tenants.

Staff supervision should include the subject and documentation will cover problems raised and advice and support given.

Professional notes will include not only actions agreed and taken but summaries of options considered and reasons for their rejection where this is the case.

10.6 Step 6 Conduct a Review

Following a death within a service, those concerned with support to the person and co-tenants and families might find it helpful to review the service response to the needs of all concerned. The purpose of the review being to build on experience, review the plan and ask how we might have done things differently. This review will include thoughts about how the person will be remembered at home, in the day centre or service. The key worker or manager would be well placed to organize this type of review.

10.7 Families

The families of people who are supported by either residential support services or the community learning disability teams (CLDT) may need some support from the service which supported their relative for some time after a death.

11. Some Roles

11.1 Support Staff

Support staff, like family members, bring with them detailed knowledge of the person including:

- Knowledge of their means of communication
- what they like, don't like
- how they cope with distressing situations
- how they may be helped through pain,
- how they may be helped to make sense of the situation they are in
- what they might decide in similar situations but without the stress and fear of the illness.

Support staff have a significant contribution to make in clinical decision making:

- in assisting medical staff in making treatment decisions with information about the person when well
- likely responses to treatments,
- health history
- ways of ensuring co-operation
- ways of supporting the person through short term discomforts of treatment.
- Impact of the person's condition on others

They will provide comfort in the last days of life and service plans must be flexible enough to permit changes so that people are supported by staff who know them well and who are not distracted by other duties,

11.2 Case Coordinator

This may be the lead clinician, care manager or other professional and is the person who identifies the roles and responsibilities of others, has accountability for overseeing the treatment plan and details of its relationship to the support plan.

11.3 Service Commissioners

It is vital that key workers and managers keep commissioners informed of diagnosis, changing conditions and needs of the person with deteriorating conditions and illness, family, co-tenants, friends and staff. This will assist the commissioners in their decision making about funding issues:

- Extra support for the staff team to meet changing care needs
- Additional needs of co-tenants brought about by the impact of the illness including a short-term change of tenancy or holiday
- Staff training needs
- Continuing support to families including, possibly for a time after a death
- Discussion about voids.



ACKNOWLEDGEMENTS

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Manchester Learning Disability Partnership
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Calderstones NHS Trust
North West Community Services
Think Quality - A Group of People who use Services.
Talbot House – A Parent Support Centre

