

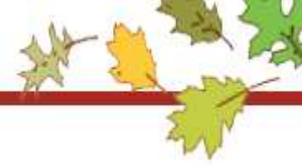
**NHS**

death & dying

It's a fact of life

# Improving End of Life Care for People with Learning Disabilities

## Resource Pack



## Acknowledgements;

*We would like to thank the following people for their ongoing advice and support of the project;*

**Carl Ellis - EoL Care Team Manager (Notts City PCT),  
Debbie O'Brian - District Nurse, (Notts Community Health)  
Stephanie Pindor - EoL Care Trainer (Notts County PCT)  
Elise Adam – EoL Care Trainer (Notts County PCT)**

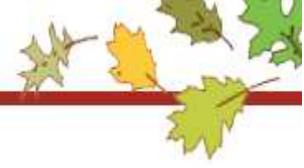
*We would like to thank the following people for contributing to this resource pack;*

Dr A Chauhan – Consultant in Palliative Medicine, Nottinghamshire County PCT.  
Felicity Court – Speech and Language Therapist, Nottinghamshire Healthcare Trust.  
Mike Deakin – Person-Centred Planning Team, Nottinghamshire County Council.  
Elaine Blinko – MacMillan Nurse, Nottinghamshire Community Health.  
Christopher Law - East Midlands Ambulance Service NHS Trust.  
Shelley Hancock - Acute Liaison Nurse, Nottingham University Hospitals.  
Ruth Harrison – Learning Disability Health Facilitator, Nottinghamshire Community Health.  
Ann Launders – Community Learning Disability Nurse, Nottinghamshire Healthcare Trust.  
Anna Oliver – Information Prescription Project Manager, Nottinghamshire County PCT.  
Mike Sergeant – Mental Capacity Act Lead Practitioner, Nottinghamshire Healthcare Trust.  
Dr M. Shemoun – General Practitioner, Bull Farm Primary Care Centre, Mansfield.  
Anne Wilson - BHF Specialist Nurse, Nottinghamshire Community Health.

*We would like to thank the following people for contributing to the project;*

'Make it happen' Drama Group; Willows Woods and Red Oaks Day Centres

Dr J. Barker – General Practitioner.  
Denise Bircumshaw - Matron.  
Dr Gregg Finn – Consultant Palliative Care.  
David Levell – Head of LD, Public Health Directorate.  
Helen Scott - Health Improvement Principal.  
Tes Smith - LD Lead, National End of Life Care Programme.



This resource pack was developed as part of a project improving end of life care for people with a learning disability across Nottinghamshire County, Nottingham City and Bassetlaw. The project was funded by the National End of Life Care Programme.

**The project was lead by;**

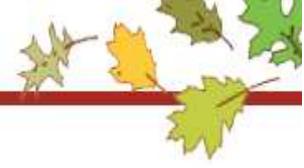


***Claire Henley***

**Learning Disability Nurse Specialist**  
Kings Mill Hospital,  
Sherwood Forest Hospital Foundation Trust

***Gemma Del Toro***

**Learning Disability Health Facilitator**  
Highpoint Cluster,  
Nottinghamshire Community Health



As a society we do not talk openly about death and dying. Even professionals find it difficult to raise the topic. This can mean that people do not have an opportunity to express their choices and caring teams do not learn about individual's preferences. This can be even worse if we make incorrect assumptions about an individual's ability to explore the topic.

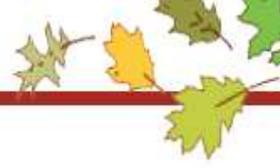
Good communication is the cornerstone of a joined up service to care for all people at the end of life. This Resource Pack for People with Learning Disabilities was developed from the Nottinghamshire End of Life care Pathway for All Diagnoses.

The Resource Pack ensures:

- Delivery of High Quality Care for all people in all locations - ensuring that those with Learning Disabilities are not disadvantaged
- The Early Identification of all people approaching the end of life
- Initiation of discussions about preferences for end of life care
- Advance Care Planning that includes; assessing needs and preferences, agreement of a care plan and ensuring regular review.
- Co-ordination of care
- Management of the Last Days of Life
- Care After Death
- Support for carers during a persons illness and after their death.

This Care Pathway is strongly supported as a method to support those with Learning Disabilities approaching the end of life and their carers, throughout Nottinghamshire.

Dr Greg Finn  
Consultant in Palliative Medicine  
John Eastwood Hospice  
Nottinghamshire



**“All people with a learning disability are people first with the right to lead their lives like any other, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens.”**

This quotation from *Valuing People: A new strategy for Learning Disability for the 21<sup>st</sup> Century* - Department of Health (2001) opens the Nottingham & Nottinghamshire Health Needs Assessment for Adults with a Learning Disability (Little & Pridgeon, 2010).

The successor document *Valuing People Now: a new three-year strategy for people with learning disabilities* - Department of Health (2009) goes on to say:

**“There is clear evidence that most people with learning disability have poorer health than the rest of the population and are more likely to die at a younger age. Their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety.”**

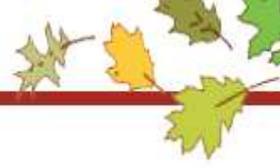
We have made, and continue to make, improvements in the ways in which we make healthcare available to our fellow citizens with learning disabilities, and life expectancy overall for this group is increasing from its previously very low base compared to the wider population.

We have not, however, addressed consistently the difficult issues surrounding End-of-Life for this vulnerable group. It has remained mainly a taboo, with reluctance to discuss the issues with the individual and a consequent failure to approach their End-of-Life care and support in a coherent way, risking distress and lack of empowerment over even the most basic opportunity to express a preference about the place to die. There may be many reasons for this, usually rooted in a genuine wish to act in the best interest of the person, but the outcome can often leave everyone involved with a profound and lingering sense of missed opportunity.

This Resource Pack demonstrates how services can work together to provide sensitive and timely support to people with a learning disability approaching the end of life, using the established good practice principles of the Nottinghamshire End of Life Pathway. It provides a clear and practical description of how specialist learning disability staff, those in general services and those with specialist skills in end-of-life care, can support each other to put the person facing end-of-life at the centre of the process, to provide the best possible care and support. Essentially, it offers the opportunity for a step-change in the sense of dignity and respect experienced by people with learning disability, and those who love and care for them, at the end of lives which may well have included more than a fair share of challenges.

I am happy to congratulate the authors and commend the Resource Pack to you.

NHS Nottinghamshire County  
David Levell  
Head of Learning Disability



## How to use the resource pack:

This resource pack was designed to signpost and support people with learning disabilities during end of life care. Below is the Learning Disability End of Life Pathway for Provision of Care, this pathway is based on the *Nottinghamshire End of Life Pathway for All Diagnosis*. The orange section highlights what further support could be offered to a person with a learning disability. The Pack is then colour coded in line with the Nottinghamshire pathway and further information on each stage can be found in the following chapters.

End of life care is very individualistic and the information set out in the chapters below may be needed at different stages of pathway.

### Green Section - < 6 – 12 months

- Who may help with End of Life Care?
- Person Centred Planning at End of Life.
- End of Life Section for an individual's Personal Health File.
- Importance of Communication.
- Breaking Bad News.
- Pain and Symptom monitoring.
- The Mental Capacity Act and making decisions during end of life.
- Information Prescriptions.
- East Midlands Ambulance Service.

### Yellow Section – Prognosis 'a few weeks'

- Continuing Healthcare
- Medication and anticipatory prescribing

### Red Section - < than 1 week

- Last days and hours
- Liverpool Care Pathway

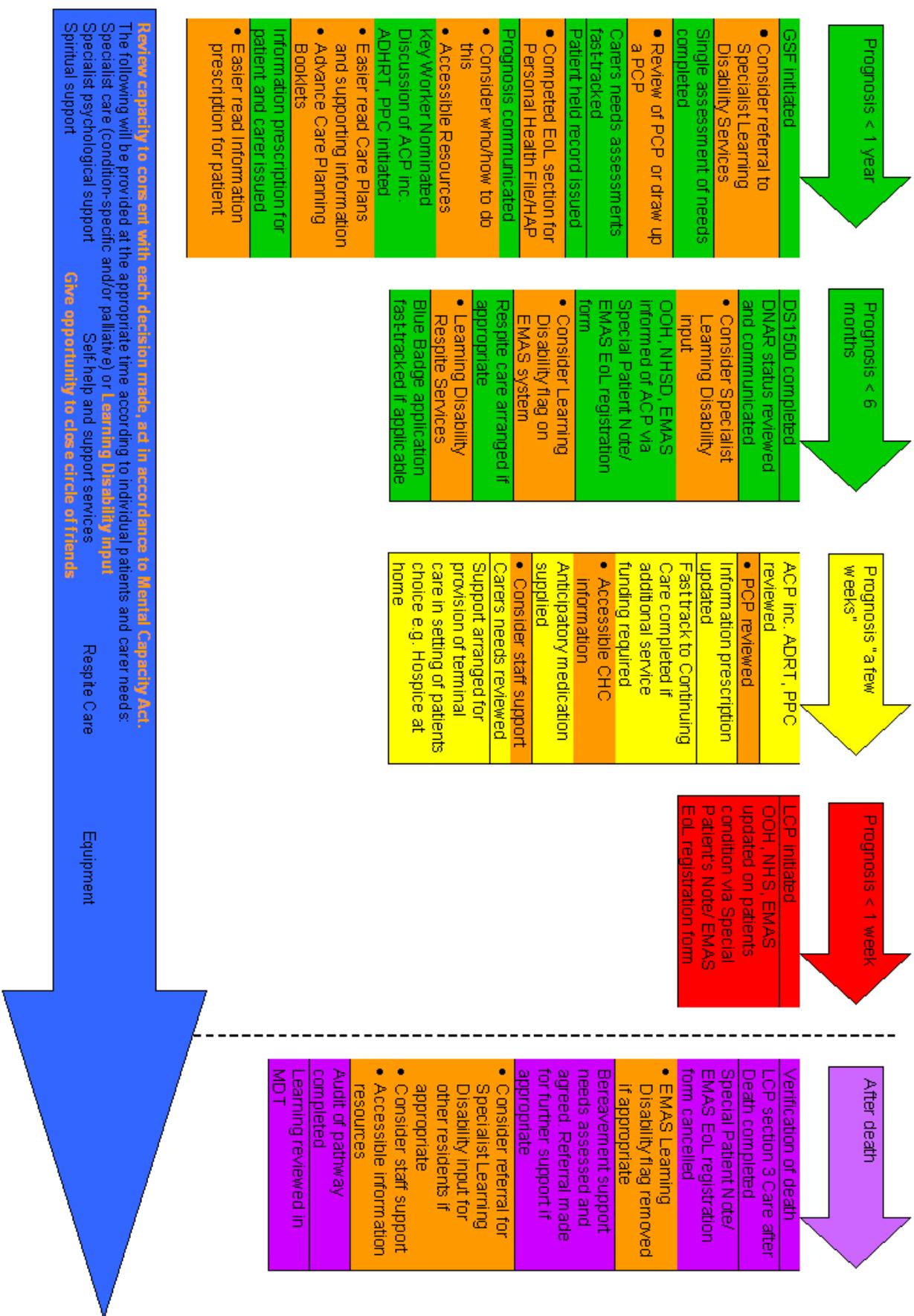
### Purple Section – After Death

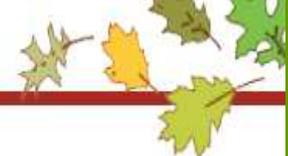
- What to do when someone dies.
- When a friend or family member dies

### Blue Section – Supporting the pathway

- Contact Chart
- Learning Disability Directory of Services
- Accessible Resources
- Professional Resources

# Learning Disability End of Life Care Pathway – Details of Care Provision





# Prognosis < 6 – 12 months

## Who can help?

### **Learning Disability Specialist Nurse/Acute LD Liaison Nurses**

The role of a Learning Disability Nurse in the hospital is to offer advice, liaison and education to staff working in the hospitals, the individual with a Learning Disability and their carers. To liaise with community teams and support services facilitating good communication.

Also part of the LD nurse role is to provide education to hospital staff about the needs of patients with a learning disability, and advice at a strategic level to influence policy and procedures within the acute setting.

A Learning Disability Nurse may support an individual with a learning disability at end of life when they access hospital care in inpatients or outpatients in these areas:

- Hospital Traffic Light Assessment.
- Helping an individual to understand what tests/treatments are taking place within the hospital.
- Helping an individual to understand their diagnosis, this may take place with other professionals.
- Liaising with hospital services to enable equal access.
- Supporting colleagues in the hospital (including End of Life Services) to understand the individual's learning disability.
- Signpost to other services that may be able to offer support.
- Supporting the individual to make decisions regarding their care in hospital.

*For contact details please see the directory of services.*

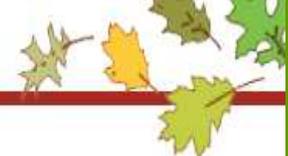
### **Learning Disability Health Facilitators**

Health Facilitators are a group of Learning Disability Nurses that are employed by Nottinghamshire County, Nottingham City and Bassetlaw NHS trusts to improve access to Primary Care for all individuals with a learning disability. The team provides support to adults with learning disabilities to help them understand, maintain and improve their physical health needs. This work includes advising carers and professionals on making adjustments in order to reduce health inequalities for adults with learning disabilities within Primary Care.

A Health Facilitator may support an individual with a learning disability at end of life in these areas:

- Health Action Planning including End of Life section.
- Helping an individual to understand what tests/treatments are taking place within Primary Care.
- Helping an individual to understand their diagnosis, this may take place with other professionals.
- Liaising with Primary Care Services to enable equal access.
- Supporting colleagues within Primary Care (including End of Life Services) to understand the individual's learning disability.
- Signpost to other services that may be able to offer support.
- Supporting the individual to make decisions.

*For contact details please see the directory of services.*



## Community Learning Disability Teams

The teams include a wide range of health and social care specialists such as; Social Workers/Community Care Officers, Welfare Rights Officers, Transition Co-ordinators, Supported Living Co-ordinators, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Psychologists, Psychiatrists and Community Learning Disability Nurses.

The health professionals within the team will provide information and advice to adults with learning disabilities covering a wide spectrum of health related issues. They are often best placed to provide support and assistance in the end stage of an individual's life due to the existing relationships and knowledge within the framework of the CLDT.

At this often difficult but vital stage of an individual's life, the health focus of the team will be on supporting the individual and their carers to understand the processes involved and providing therapeutic interventions to assist with both the physical and emotional implications. They will be integral to the liaison amongst wider members of the multi-disciplinary team and to the facilitation of all required planning and implementation of the individual's care needs. The community learning disability team is available as a resource to the individual and their carers, to enable informed, considered and fairer access to health care at a time when it is needed most.

*For contact details please see the directory of services.*

## Specialist Palliative Care Team

The Specialist Palliative Care (SPC) team works exclusively in palliative care and have expertise in addressing complex patient and family /carer needs. These needs include uncontrolled pain and other symptoms, and complex psychosocial problems. It may be necessary to involve the SPC team at any stage of the pathway. Holistic care is delivered using a multidisciplinary approach including medical and nursing staff, Chaplaincy, social workers, physiotherapist, occupational therapist, pharmacist, clinical psychologist and complementary therapists. Care is delivered in a variety of settings such as the hospice and specialist palliative care unit, hospitals and community. Types of services available include in-patient care, out-patient clinics, day care as well as support from the community Macmillan nurses, Hospice at Home Team and the hospital palliative care team. Locally, the bases for these services are John Eastwood Hospice, Nottinghamshire County PCT and Haywood House Macmillan Specialist Palliative Care Unit, Nottingham University Hospitals NHS Trust.

The SPC team are available to give advice and support to other healthcare professionals. Education and training programs are provided to improve the standard of general palliative care.

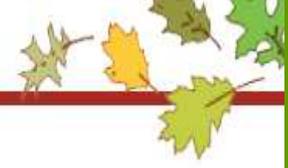
*John Eastwood Hospice – 01623 622626*

*Nottinghamshire County PCT – 01623 414114*

*Haywood House – 0115 993 4977 - ext 54977*

*Nottingham University Hospitals - 0115 924 9924*

*Bassetlaw SPC Team – 01777 863312*



## Macmillan Nurse

Macmillan nurses are experienced nurses who have specialised in palliative care and work in an advisory capacity rather than delivering “hands on” care. They are part of the Specialist Palliative care team. Macmillan nurses provide help and advice from the point of diagnosis onwards. The aim is to ensure that individual’s and their carers have access to the best information, treatment and support. Macmillan nurses support those with cancer and other illnesses.

Macmillan nurses work with GP’s, District nurses, Hospital doctors and nurses, Hospice staff and other health professionals involved in your care. Macmillan nurses can help in the following ways

- Advise and guide individual’s through the different treatments available
- Provide advice and information on any symptoms that you may experience
- Identify sources of practical help, financial benefits, written information and other helpful services available
- Provide emotional support and time for individuals and their carers to discuss any concerns or questions you might have
- Staff support, GP’s, Nurses, Allied Professionals
- Bereavement care
- Macmillan nurses can see individuals in their own home, hospital wards, outpatients department, hospice or in care homes.

Macmillan nurses may only see individuals once or it may be more often if required. This will be negotiated with the individual and is also dependant on their needs.

*Mansfield, Ashfield, John Eastwood hospice – 01623 622626*

*Newark and Sherwood area - 01636 685881*

*Nottingham City – 0115 962 7619*

*Bassetlaw – 01777 863312*

## End of Life Care Trainers

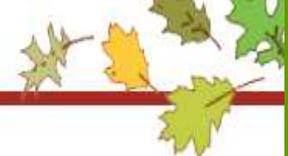
Provide free training to health and social care providers on the use of the Nottinghamshire End of Life Care Pathway, associated best tools of practice and basic palliative care skills. This training compliments that provided by specialist palliative care services.

The pathway aims to improve the quality, co-ordination and access to services for all adults in the last year of life and to provide those approaching the end of their life with more choice about their preferences for care.

It recognises the need to identify and support carers and families throughout this time and in the bereavement period.

Training offered includes;

- Overview of the End of Life Care Pathway
- Advance Care Planning
- Anticipatory Prescribing
- Gold Standards Framework for GP’s/Community Nurses
- Use of the Liverpool Care Pathway
- Basic palliative care and recognising the dying phase
- Syringe driver training for care home staff
- Support with accessing and registering for the Gold standards Framework for Care Home
- Dementia and end of life care



To support the implementation of the Eolc Pathway in practice, the Eolc Trainers have also produced and provided Eolc Toolkit Folders/resource packs for GP's/Community nurses and Care Home staff. These toolkits and updates can be accessed via the Learning & Development website [www.nottsladd.nhs.uk](http://www.nottsladd.nhs.uk) or Nottinghamshire County Workforce Planning

## **GP**

The GP is the key member in provision of palliative care to individuals with a learning disability. Starting from pre-diagnosis, through the process of diagnosis, treatment, continuing illness or death and into the bereavement stages.

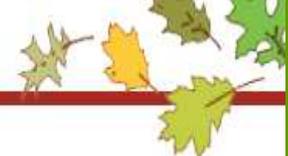
- Planning of care with the Specialist Palliative Care team.
- Anticipation of any possible problems.
- Regular medical assessment of symptoms and advice about further management.
- Co-ordinate home care support for individuals with complex needs who wish to stay at home.
- Integrate the medical, psychological and information requirements for the individuals care.
- Assess the need for specialist help and advice for individuals and liaise with their family/carers.
- Prescribe and provide help as needed.
- Notify the Out of Hours team, and provide them with the information needed about the individual.
- Decide with the individual and family/carers about preferences and future care, to keep the individual in control even at the end of life.

## **District Nurse**

End of Life care is a major part of our core service provision in the community setting. District Nurse Caseload holders are often the named "key worker" for individual's who are referred from secondary care. This role is very important as it enables greater communication of important patient information by all involved with regard to diagnosis, prognosis and advance decisions etc.

As a team of experienced and skilled practitioners we aim to deliver holistic care to the individual in their own home environment together with the wider specialist multi disciplinary team i.e. GP, Macmillan Nurse, Hospice at Home. This care could be in the form of regular support visits or more specifically treating and monitoring pain and symptom management. It is very important that as a team we are able to establish a relationship with individual, their family and carer's as early as possible as this can prove to be beneficial and improve the quality of care given from the beginning through to the end of a individual's journey.

*To contact Community Nursing Services please ask the GP.*



## Specialist Nurses

There are many different types of Specialist Nurses, these may include; Community Matron, Tissue Viability Nurse, Oncology Nurse, Stroke Nurse, Respiratory, Colorectal Nurse, Diabetes Nurse, Epilepsy Nurse, Lung Cancer Nurse, Breast Care Nurse and Parkinson's Nurse. Specialist nurses all have different roles but all with the objective of meeting the needs of the individual and carers. One example of the role is outlined below.

### **British Heart Foundation Community Heart Failure Nurse Service**

The British Heart Foundation Community Heart Failure Nurse Service allows care for individuals with heart failure to be provided closer to the individual's home, working in partnership with GP practices. This facilitates the movement of individual's between primary and secondary care as their condition dictates. The aim of the service is to optimise the management of individual's with chronic heart failure by providing tailored education, review of medication, advice and support. Clinics, visits and telephone contact from a heart failure nurse specialist will be determined by individual need. This will reduce unnecessary admissions and readmissions to hospital as well as improve the quality of life for individuals.

The service enables GP's, as well as cardiologists, to refer patients who are newly diagnosed or present with worsening symptoms of Left Ventricular Dysfunction confirmed by Echocardiogram. Referral forms and nurse contact details can be found on the intranet.

The service is also available to provide education and support to primary care staff and to provide palliative care support for heart failure patients and their carers.

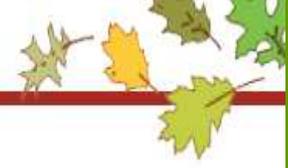
In the case of individuals with learning disabilities, who has heart failure, being referred to our service we would require support and advice from the Learning Disability Health Facilitators and equally can provide advice to them from a heart failure perspective.

### **Community Matron**

The Community Matron is an experienced nurse who provides nursing care and case management to people with single or multiple complex long- term conditions. Advanced clinical skill allows the Community Matron to identify early warning signs, investigate and diagnose exacerbations of illness, and arrange for treatment to be implemented. A proactive service is provided in order to communicate and work collaboratively with all health professionals, carers, relatives and social services.

All patients with learning difficulties and with a long- term condition e.g., COPD, CHD, Diabetes who are referred to the service will be supported and treated without discrimination. Despite any communication challenges we may encounter, we will endeavour to liaise with their family and carers accordingly. We can provide education of the natural progression of conditions and can establish individualised care plans to empower carers and families to identify any changes in the health status, seeking professional advice where appropriate ensuring the right carer at the right place and at the right time.

*These are just some of the professionals that may help support an individual at end of life; we acknowledge that individuals have different needs therefore requiring alternative avenues of support. Please ask the professionals involved in the individual's care for further information on services*



# Person Centred Planning at End of Life

Making choices and decisions is important to all people during 'end of life' including those with a learning disability. Discussing and planning a person's wants and wishes is important throughout their life, this is often forgotten once a person is on the End of Life Care Pathway but is vital to the person having a quality of life during this time.

## What is Person Centred Planning?

**Person Centred** means doing things the way the person wants things to be done. Person Centred Planning is a way of helping people to think about what they want now and in the future. It is about supporting people to plan their life and work towards their goals. In person centred planning the person is in charge but a group of people may support the person to plan parts of their life.

Person centred planning might be able to;  
*Help the person make choices about things in their life.*  
*Help the person tell other people about what is important to them.*

## What do Person Centred Plans look like?

Person Centred Plans look different for every person, but they should **always** be **colourful**, **creative** and **fun**!! Person Centred Planning does **not** look like a care plan. There are different types of Person Centred Planning.

## Person Centre Plans, the tools.

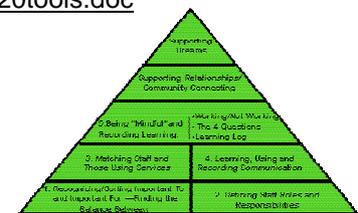
There are a number of tools for person centred planning. They all follow the below principles:

- The person is at the centre.
- Family and friends are partners in planning.
- The plan focuses on gifts and capacities and looks to the future.
- Planning builds a shared commitment to action.
- Planning is an on-going process.

Which tool is used depends upon the person and their life, see the following link for further information. <http://www.nottscountypb.org/Libraries/Local/734/Docs/PCP/pcp%20tools.doc>

## Person Centred Thinking (see appendix 2)

Person Centred Thinking is a way of working, there are a number of tools which people who provide support can use to help them work in a more person centred way.



- How to sort what is important **to** a person from what is important **for** them.
- How to address issues of health, safety and risk whilst supporting choice.
- How to identify what the core responsibilities are for those who provide paid support.
- How to consider what makes sense and what does not make sense about a person's life.

- How to ensure effective support by matching characteristics of support staff to the person's needs.

The Person Centred Thinking tools are fundamental to all other person centred approaches.

If you want to know more about Person Centred Planning you can phone and ask.



**Nottingham City**  
**Cat Wilson**

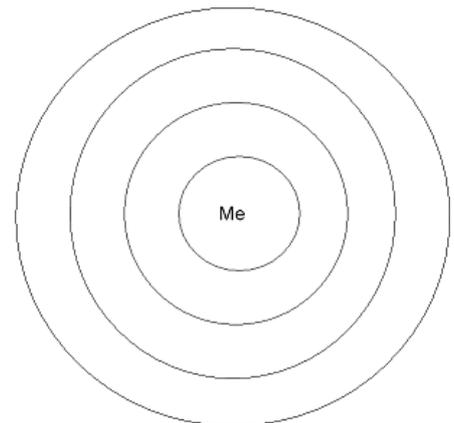
Telephone 0115 915 0149 or email [cat.wilson@nottinghamcity.gov.uk](mailto:cat.wilson@nottinghamcity.gov.uk)

**Nottinghamshire County**  
**Sarah Craggs or Mike Deakin**

Telephone 01623 434 294 or email [sarah.craggs@nottscc.gov.uk](mailto:sarah.craggs@nottscc.gov.uk)  
[mike.deakin@nottscc.gov.uk](mailto:mike.deakin@nottscc.gov.uk)

## Circle of Support

A **circle of support** is describing a number of people who provide support and/or friendship to a person with a learning disability. Everyone within the circle should know the person well and care about what happens to them. Having a circle of support is a good way of helping the individual to achieve the goals outlined in their person centred plan. It may also help to support with any changes they may need to make in their life. It may be a good idea that regular circle of support meetings take place.



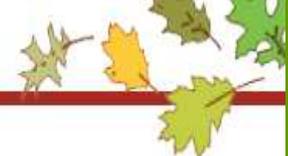
## Personal Health Files/Health Action Plans



The Government says in `Valuing People NOW` 2008 that every individual with a learning disability should be offered a health action plan and family doctors should know all their patients who have a learning disability. Personal Health Files and Health Action Plans are a good way to help people look after their health needs. They help people to keep all their health information in one place.

Successful communication during an individual's end of life is vital to ensuring high quality of care, using a Personal Health File can play an important role when used effectively. To ensure all essential information is included, a section to be used during an individual's end of life and added into a Personal Health File is available. To obtain a copy please contact your Learning Disability Health Facilitator.

*For contact details please see the directory of services.*



# Importance of Communication

## Good Communication

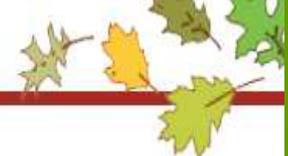
Effective communication is of key importance at the end of life. Many people with learning disabilities have significant difficulties in communication; with both expressing themselves and understanding what others say. Strategies to support optimum communication at this time are crucial:

### Good Practice

- Ensure someone is always accompanied to appointments by someone who knows them and their communication needs well.
- Try and avoid multiple appointments if possible – one stop shop is best!
- Make sure glasses and hearing aids are worn
- Prepare someone before a meeting or Doctor's visit so they know what is going to happen and what to expect
- If possible have a preliminary discussion with carers/ speech and language therapist **before** an important meeting so that relevant resources can be prepared in advance.
- Remember that anxiety, fatigue, recent epileptic seizures, medication and the environment can all have an effect on a person's communication.

### Helping Someone's Understanding

- Ensure you have the individual's attention before talking to them - a quiet environment helps.
- Wherever possible **show** someone something as well as telling them.
- Back up speech with non verbal communication – signs, gestures and facial expression.
- Support speech and written information with 'visuals' such as photographs, pictures and symbols.
- If an individual has a communication book – please use it!
- Do not speak too quickly.
- Use short, simple sentences.
- Avoid complex or abstract vocabulary and explain new information words.
- Check an individual understands by asking them to tell you what have said – NOT by simply asking 'Do you understand?'
- Allow plenty of time for an individual to process information
- Simple summaries of discussions and information should be given to carers. They can then go through this several times with someone – to ensure it has been properly understood.
- If you are unsure whether someone understands some of the concepts involved in end of life care contact the speech and language therapy service. They will be able to establish a person's level of understanding and provide visual resources as needed.
- In the late stages of an illness **touch** can be very important - and reassures someone that they are not alone.



## Helping Someone to Express Themselves:

- Allow plenty of time.
- Reduce background noise.
- Sit face to face with the individual and in a good light.
- Be alert to attempts at non verbal communication, e.g. eye contact and facial expression.
- Be aware that being able to speak does not necessarily mean an individual has good understanding.
- If you don't understand what someone says, ask them to say it again more slowly or to try and say it another way.
- If an individual has a communication book or communication aid – please encourage them to use it.
- Similarly, if an individual uses signs ensure there is someone available to sign with them.
- If important pictures/symbols that help to express end of life wishes are needed, contact the speech and language therapy service for support.
- Involve a 'communication partner' who knows the individual well and can help 'mend' any communication breakdowns that may occur.

*For contact details please see the directory of services.*

## Assessment and Monitoring tools

### Hospital Traffic Light Assessment tool

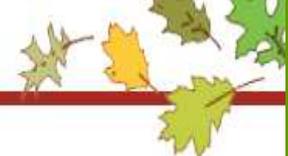
Within Nottinghamshire County and City, the "Hospital Traffic Light Assessment" (HTLA) is being introduced into the community for individuals with a learning disability to bring into hospital with them; the document is based upon the Gloucestershire NHS Trust TLA. The TLA provides staff with specific, person centred information to help support the individual through their time in hospital.

Following the colours of a traffic light, the **red** section details essential information; including personal details, how to approach the individual to carry out medical interventions etc. The Nottinghamshire document has been amended to include information on if an Advanced Decision or directive has been made for future care.

The **Amber** section highlights the areas an individual would need support with in hospital, specific and concise information is needed to help staff support the individual with a learning disability effectively. The areas covered are communication, information sharing, seeing/hearing, Eating, Drinking, toileting, mobility, medications, pain, sleeping, keeping safe, personal care and levels of support.

The **Green** section details the individual's likes/dislikes and what is important to them, this could detail anything from food preference, routines, hobbies or how people like to be talked to.

The HTLA is used as a baseline for how an individual is when well, although in relation to end of life care, the HTLA provides information of what is important to the individual overall in their life and what is important for them to be supported with in relation to hospital care. As also described previously, the HTLA documents if an individual has made an advance directive on any future care, this would help in end of life situations if an individual is unable to



communicate wishes and preferences, that these can be honoured. This also relates to the section where it documents if a lasting power of attorney has been appointed, this person would legally act on the person with a learning disability's behalf if the person loses capacity at the end of life. Hospital staff would be aware that the person highlighted as a lasting power of attorney should be consulted on decisions.

### **An example of how the HTLA was used in end of life care:**

*A lady who was on the end of life care pathway had been given information on her diagnosis with a family member, and provided the information in a way which she understood. This enabled her to make an informed decision on how and where she would like to receive end of life care. The document also highlighted that she had a cuddly bear, and it was important to the lady to have the bear with her in situations where she was afraid or anxious (i.e. Radiotherapy treatment), which comforted her immensely. The lady was also very reticent to "bother" staff if she felt in pain, so staff became aware that they needed to directly ask the patient if she felt in pain, or regularly offer pain relief.*

### **DisDAT**

This tool is used to identify and monitor distress in an individual with a learning disability. The tool looks at describing a person's usual self in communication, appearance, vocal signs and postural observations this enables any signs of distress to be monitored and acted upon in a timely manner.

The tool was developed by Lynn Gibson, Dorothy Matthews and Dr Claud Regnard.

For the latest version of DisDAT see [www.mencap.org.uk](http://www.mencap.org.uk)

### **My Pain Profile**

*"Imagine feeling severe pain and not understanding what is happening, nor even being able to ask for help and information. That is frequently the case for people with profound learning disabilities who cannot communicate verbally. Yet when distress and anxiety alter their demeanour, it is often dismissed as 'challenging behaviour' until the illness causing the pain reveals itself in some other way." (R. Astor, 2001)*

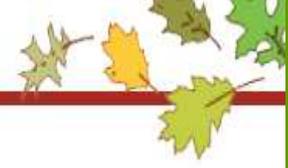
My Pain Profile aims to support the identification of pain in individuals that may not be able to communicate verbally when pain is being experienced.

The 'My Pain Profile' can be completed at anytime by an individual or by a person that knows them well. This can then used with the 'Assessment of Pain' insert to help identify if an individual may be experiencing pain and relief may then be sought.

The 'My Pain Profile' can be used in a variety of settings to help to manage a person's pain within the home environment or inform health professionals caring for the individual during a hospital admission.

The aim of the tool is for people caring for and/or supporting the individual to stop for a moment and think about non-verbal signs of pain!

This can be downloaded from; [www.nottinghamshirelearningdisabilitypartnershipboard.org](http://www.nottinghamshirelearningdisabilitypartnershipboard.org)



# Breaking Bad News

Being told that a person has a life limiting condition is a difficult process for all involved. The East Midlands Cancer Network and Palliative Care Group have produced guidelines for Healthcare Professionals to help them break bad news to patients, families and carers. These guidelines include an 11 step process as a framework to follow, this section outlines additional factors that may need considering when delivering bad news to an individual with a learning disability.

*'The basic model within these guidelines can be used for patients with learning disabilities but additional factors need to be taken into account. The patient's nominated key worker may be of particular value supporting the patient. There are a number of resources which can help.'* (Breaking Bad News Guidance, East Midlands Cancer Network, 2010)

Outlined below are the additional factors and resources available.

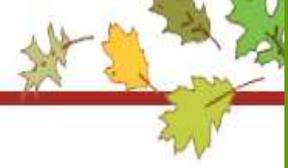
## **11 Steps to Breaking Bad News:**

### **Step 1 - Preparation and scene setting**

- *Know all the relevant facts* – Does the person receive input from a learning disability professional? Is it beneficial to make contact prior to delivering the news? How does the person communicate and what is their level of understanding? Will accessible resources be needed to support the verbal information? Consideration should be given to who has the necessary skills to be the deliverer of the news; it may not be the doctor, but someone familiar to the individual with the doctor's support.
- *Who should be present* – If the individual is assessed as lacking capacity, is it in their 'best interests' to be present? As some may find this environment distressing. Does the individual have an advocate? Wherever possible, allow the individual to decide who will support them through this process.
- *Set time aside* – Allow more time for the appointment than usually allocated, as the individual may need extra time in processing and understanding the information given.
- *Ensure privacy and set the scene* – Where should the news be delivered, would an alternative place to the health setting be more appropriate? Consider any sensory impairment.
- *Introduction* – Consider your appearance, some people with a learning disability find a health uniform threatening and scary! Explain your job role using simple language but don't patronise.

### **Step 2 – What does the patient know?**

- When checking an individual's understanding of what is happening to them, ensure again that the information is given at a level the person understands i.e. short, simple language,



photographs and pictures, objects of reference. Consider seeking advice from a learning disability professional.

- Additional information may need to be sought from other involved in their care.

**Step 3 – Is more information wanted at that time?**

- Observe for non-verbal cues that the individual is declining further information at this stage. The person(s) supporting the individual may be best placed to advise if this is the case.

**Step 4 – Give a warning shot**

- Again, ensure this is given in a way the individual will understand.

**Step 5 – Allow the patient to decline information at this time**

- Do not assume that an individual with a learning disability will not require further information due to their level of understanding.

**Step 6 – Explain (if requested)**

- Use alternative forms of information if needed, seek advice from a learning disability professional if necessary.

**Step 7 – Elicit and listen to concerns**

**Step 8 – Encourage ventilation of feeling**

**Step 9 – Summary and Plan**

- Does the individual require a plan in an easier read or accessible format? Providing a written summary will allow the individual to review at their own pace the information given. The plan should be person-centred and be a holistic view of the individual.
- A section covering end of life is available for the individual's personal health file which may be introduced at this stage to document all relevant information. (see page 14 for further information)

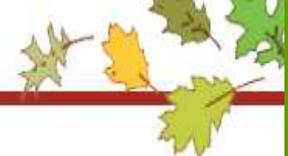
**Step 10 – Offer availability and support**

- When offering further appointments write down the dates and times for the individual. If the individual lives independently, contacting the individual by telephone the day before is often beneficial.

**Step 11 – Communicate with the team**

- Ensure communication is made with any professionals involved from learning disability services.
- Any letters sent to the individual need to be written in simple language but still retain all relevant facts.

An information prescription may be useful to continue effective discussions with the individual; these are available in an easier read format with various supportive resources.



## Symptom monitoring

As a person progresses through the end of life pathway, it is natural for them to experience some symptoms, including pain, relating to their condition. Below are a few of the more common symptoms present during end of life, although these will be dependent upon an individual's condition and prognosis. It is important to document and monitor any symptoms experienced and discuss with the health care professionals involved how they can be minimised and managed.

### Breathlessness

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

#### Things to consider:

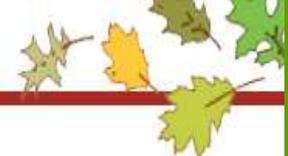
- Try to reassure the individual and explain to them in a way they understand what is happening, give some one to one support until the symptoms ease.
- Look at the position the individual is seated or laid in; does the individual need another pillow to provide more support, does this ease the problem?
- Is the individual hot? Will opening a window or having a fan in place help?
- Can the individual be talked through relaxation techniques to help with their breathing?

### Tiredness and lack of energy

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

#### Things to consider:

- Plan so that the individual has time to rest during the day but also has time to do things they enjoy. Consider creating an accessible timetable.
- Help the individual to be realistic in planning their days/weeks after their diagnosis; they may have been active on a daily basis however now the individual may need a rest day in between.
- Explain to friends and family that the individual may not have the energy to do some of the things they enjoyed previously.
- Use imagination and be creative in supporting the individual to maintain social relationships when fatigue prevents them from going out.
- Try to maintain the individual's usual sleep pattern during the night and wake the same time each day.
- Encourage the individual to participate in some form of exercise.
- Try to keep a steady temperature in the individual's room.
- Encourage the individual to have supper so a 'growling tummy' won't wake them.



## Constipation

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

### Things to consider:

- Keep a food diary to monitor the individuals fibre intake, a health professional can offer further advice.
- Try to encourage fluids.
- Maintain gentle exercise when possible.
- Tell the individuals GP or nurse as the problem maybe due to medications the individual is currently taking. Do not stop or alter any medications without the advice of a health professional.

## Loss of appetite

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

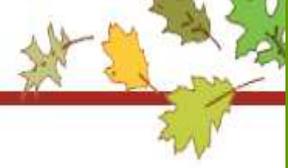
As individuals become more ill their metabolism slows down. The body cannot digest food as well therefore it is very important not to insist that people eat.

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

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

### Things to consider:

- Have a list of the individuals ‘favourite’ foods and encourage these.
- Keep a food diary to monitor the individual’s intake.
- Encourage little and often and ensure that foods are calorie rich such as adding cheese, using full fat milk and yoghurts.
- Try changing the plate size so that the individual is not over faced by the amount of food.
- Make the food look nice using foods bright in colour and flavoursome.
- Have snacks available for when the individual wants something straight away.
- Contact the individual’s health professional to discuss use of ‘build up supplements’.
- Consider the environment, is it relaxing, familiar and comfortable for the individual to eat in?



## Feeling sick and vomiting

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

### Things to consider:

- Encourage the individual to avoid fatty, greasy and fried foods.
- Some individuals find eating drier foods such as crackers or toast in a morning helpful.
- Try having drinks in-between meals rather than with food, some individuals find fizzy drinks to be a remedy.
- There maybe other physical reasons for the symptom, seek further advice from a health professional.
- Encourage little and often rather than a big meal.
- Check with the doctor/nurse to see if the individual has medication to help with the symptom or their current dose may need to be increased by the health professional.

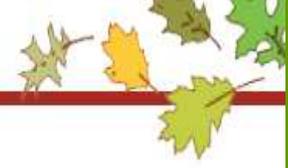
## Mouth problems

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

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

### Things to consider:

- Maintain regular mouth care, a smaller and softer tooth brush may need purchasing if the mouth is sore, good lip care is needed and the individual may need Vaseline or lip balm applying regularly.
- Try to cleanse the mouth with unsweetened pineapple juice.
- Encourage the individual to avoid foods which may be dry or difficult to manage when having a sore mouth encourage plenty of sauces and gravy with meals.
- Is the individual on medication to help manage their saliva, if so speak to the health professional about the dry mouth as this may need reviewing.
- Try to encourage the individual to drink through a straw.



## Eating and Drinking

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

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

### Things to consider:

- Does the individual require assessing by a dietician for supplements?
- Does the individual require assessment by a speech & language therapist to assess their swallow?
- Might the individual need adapted cutlery, seating, environment to help manage their difficulty?

## Mobility

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

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

### Things to consider:

- Think about a referral to physiotherapy? Is there an exercise program to help the individual maintain their mobility?
- Does the individual require specialist equipment now to maintain their mobility?
- Is the individual tired and lethargic which results in problems with their mobility?
- Is the individual in pain or discomfort, resulting in an unwillingness to mobilise?

## Complementary Therapies

Many people with learning disability enjoy complimentary therapies during their everyday life. These could be particularly helpful to an individual during end of life to improve relaxation and comfort.

Some examples of different forms of therapy are;

*Aromatherapy* – The use of natural oils with therapeutic properties.

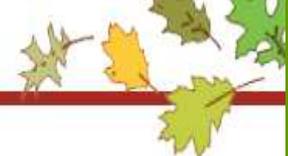
*Massage* – To help individuals relax, sooth muscle pain and general comfort from contact.

*Reflexology* – Specialised foot or hand massage.

*Acupuncture* – Acupuncture needles inserted to different parts of the body to affect the flow of energy.

*Art therapy* – To help people express themselves through art.

*Music therapy* – To help people express themselves through music.



## The Mental Capacity Act and making decisions at end of life.

The Mental Capacity Act 2005 provides a framework for decision making on behalf of those over the age of 16 who lack capacity to make a decision about a health or social care issue.

### **What is capacity?**

Broadly speaking, capacity is the ability to understand the issue, retain and process the information about it so as to come to a choice, and communicate the decision about the issue in any way.

### **Planning for future incapacity?**

An individual can make decisions now, while they have capacity, for a time when they may lack capacity in the future. This ability to plan for future incapacity is a right for all people including those who have a learning disability. The Mental Capacity Act clarifies the rules relating to planning for future incapacity.

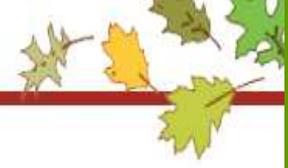
### **What's in a name?**

There may be some confusion about terminology. Can someone set up an 'Advance Directive', a 'living will' or an 'advance statement'? An advance statement in Scotland has a different meaning and legal status to an advance statement made south of the border. 'Advance Directive' is old legal terminology which has fallen out of use – except perhaps (as with the term 'living will') – with the public.

The Mental Health Act Code of Practice (Chapter 17) refers to advance decisions and to advance statements. The Mental Capacity Act Code of Practice (Chapter 9) refers to advance decisions. Chapter 5 of the Mental Capacity Act Code of Practice refers to statements of wishes and feelings in the context of making a decision in a person's best interests. Professionals, carers, and anyone advising on the subject should be clear about the difference between advance statements and advance decisions to refuse treatment and be able to help the person with a learning disability to understand the difference.

### **What is an advance statement?**

If a person is over 16, he/she can express their wishes relating to future care, and relating to treatment that they would prefer (such as what medication or care works well for them in a crisis), who they would want (or not want) to be contacted in the event of admission to hospital – in fact anything that is important to them that they would want carers to take in to account if they were unable to tell them. The list could be very short or very comprehensive and will, of course, differ from person to person. This is an advance statement. This information is not legally binding on doctors or other professionals but the law requires the bits of it that are relevant to a decision about the person who lacks capacity to be taken into account. This must be evidenced in the decision maker's notes.



## **What is an advance decision to refuse treatment?**

In amongst their expression of wishes there may be a desire not to have a particular medical treatment in the future. Because this is a desire not to have a medical treatment, it is an advance decision to refuse treatment. The person has to be over 18 to do this. 'Refuse' is a key word – a person cannot demand treatment in an advance decision (in fact they cannot demand treatment at all!). 'Treatment' is also a key word. It is about medical treatment - not any other aspect of care.

An advance decision could be made either verbally or in writing in most circumstances. So, the person could express their wishes about treatment refusal verbally, but there are disadvantages to that as it may be difficult to prove who said what and when. It is advisable to write the requirements down and be very clear about exactly what treatment is being refused and the circumstances in which it would be refused. The person should discuss their requirements with the doctor responsible for their treatment, although they do not have to get their agreement or permission. An advance decision to refuse treatment that is clearly expressed and is applicable to the treatment in question is likely to be legally binding on doctors.

It is important to recognise that if the person wishes to make an advance decision to refuse life sustaining treatment - for example terminal cancer treatment - the law requires specific formalities to be undertaken. The advance decision must be in writing, signed, witnessed and signed by the witness, and contain wording to say that the refusal is to apply 'even if life is at risk'. Note that the requirements are for the advance decision to be signed – not necessarily by the person. If the person with a learning disability is unable to write but is able to make his requirements known he/she can get someone to sign on his behalf. It must be clear that the person is signing on the other person's behalf - and under his instruction - and this must be witnessed.

## **Preferred Priorities of Care**

This is a form of advance care planning that can give the individual the opportunity to think about, discuss and document their wishes, and lets people supporting them know about what they want. This document is used across all end of life care services and an easier read version has been developed for people with learning disabilities.

*A copy of this document can be downloaded from*  
[www.nottinghamshirelearningdisabilitypartnershipboard.org](http://www.nottinghamshirelearningdisabilitypartnershipboard.org)



## What about patients detained under the Mental Health Act?

If the person is a detained (sectioned) patient it is important to know that the law currently allows refusal of treatment for a mental disorder to be overridden if doctors consider that the treatment that the person is refusing is the only treatment that will work in their case. It does not mean that their refusal will automatically be overridden, and doctors must clearly demonstrate that it is medically necessary to override their wishes to refuse the treatment. A person can still refuse treatment for a physical condition that is unrelated to their mental disorder - such as cancer.

## How can someone get help to set out my wishes and requirements?

Nottinghamshire Healthcare Trust has produced booklets in different styles and they are available for anyone with a learning disability if they wish to use them, although they are under no obligation to do so. The person may want to ask their clinical team about the availability of those booklets. In addition an advocacy service may be able to help.

positive Nottinghamshire Healthcare NHS Trust  
positive about mental health and learning disability



**Advance Statement:**  
What I want to happen if my mental health gets worse

 Name:

 Date:

positive Nottinghamshire Healthcare NHS Trust  
positive about mental health and learning disability



**my choices for future care**

I have put information in this booklet so that people caring for me will know what my wishes are if I am not able to tell them.

Name:

positive Nottinghamshire Healthcare NHS Trust  
positive about mental health and learning disability



**treatment I don't want when I am ill**

Information about medical treatment that I do not want. To use if I become unable to make or tell people my own decisions.

Name:



## Information Prescriptions

Information prescriptions offer patients and their carer's timely and relevant information at the point that they need it most. Information can be about anything from their condition to leisure activities, benefits advice and support groups to name but a few. Information prescriptions are a way of ensuring you are able to provide this information to patients and carers quickly and easily without impacting upon your day-to-day job role.

### **Who are information prescriptions for?**

Information prescriptions are for individuals with long-term health and social care needs and their carers.

### **What's inside an End of Life information prescription?**

Examples of information that may be included:

- Your condition and what may happen in the future
- What is Palliative Care
- Help and support available
- Voluntary, support and community groups
- Ways to help me
- Benefits, legal and financial advice
- Medication and treatment

### **Information prescriptions for a person with a learning disability.**

An information prescription is available in an 'easier' read format for individuals with learning disabilities. This prescription of information will then be provided in a more accessible format to aim to meet individual need.

Information can also be provided in other formats for family/carers.

**For further information on information prescriptions please visit;**



**NottsInfoScript.co.uk**

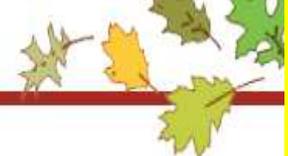


## Ambulance Service

When you are caring for someone at home there might be a time when you feel that an ambulance needs to be called. Locally East midlands ambulance service gives emergency care to patients and transports them to hospital when necessary. EMAS have educated their staff about people with learning disabilities and all ambulance crews have a set of symbols which they can use to help communicate better with people with learning disabilities.

The ambulance service has a system in place so that healthcare professionals can inform them that someone has an end of life diagnosis. The system holds basic information based on the persons address. Detailed instructions as part of a care plan should be left in the patient's home. The system can register that a patient is not for resuscitation, Does not wish to be transported to hospital for a specific condition, Has a care team who should be contacted in the event of an ambulance attendance, Has a specific care plan detailing wishes (a copy of which is with the patient).

The ambulance service will then check when they arrive at the home address and therefore be able to treat the patient appropriately and according to their wishes. The healthcare professionals involved in the patients care must ensure that the ambulance service is notified of any changes, including when the patient has died.



# Prognosis ‘a few weeks’

## Continuing Health Care

NHS Continuing Healthcare is a package of care arranged and funded by the NHS to meet the physical and/or mental health needs caused by an individual’s illness. It can be provided in any setting including a care home, hospice or own home. A referral can be made by an appropriate healthcare professional.

For any individual with rapidly changing needs, there is a fast track process in place to ensure an appropriate care package can be arranged as quickly as possible. Once a care package is in place the individual will be formally assessed based on their individual needs, and an individual will receive ‘Continuing Care’ funded if assessed as having a *primary health need*.

The benefits an individual usually receives may be affected should Continuing Care funding be arranged. In some cases this may identify that NHS Continuing Care funding is not necessary for the ongoing care.

Most local continuing health care teams have registered nurses trained in learning disabilities to assess individuals.

An easier read information leaflet on Continuing Healthcare funding is available with an information prescription.

## Medication

Medication can be used to relieve symptoms and for pain relief, at the end of life stage consideration may be needed about how medication may be given. Medications should be reviewed regularly and may change on a regular basis.

Medications can be given via different routes and different forms:

**Tablets:** Some individuals with a learning disability may find it difficult to take tablets and this often becomes a problem for people at end of life. If you notice the individual chewing the tablet or having difficulty swallowing the tablet then this needs reviewing by the GP.

**Liquids:** Some medication can be given in liquid or syrup form, these maybe easier for the individual to swallow but sometimes they can taste unpleasant.

**Patches:** Worn on the skin patches stay in place for several days and medication is absorbed via the skin.

**Injection:** Normally given by nursing staff

**Syringe Driver:** Some individuals at end of life may require a syringe driver; this is a small portable device with a fine needle that is inserted under the skin so that medication can be given easily to help symptom control.

### Pain Management:

Pain is only one symptom that's recognised at end of life individuals may suffer other symptoms such as breathlessness, loss of appetite, problems with continence and constipation. It's important to remember that some individuals with a learning disability are unable to tell us if they are in pain, they are therefore reliant on family, paid carers and professionals to be able to observe an individuals behaviour and note changes which may indicate distress.

For useful tools used  
in Nottinghamshire  
please see:

*DisDAT Tool*  
*Pain Profile*

Once a baseline has been obtained to identify pain indicators it is important to monitor the effectiveness of any pain medications given and document this in the person's Personal Health File (orange section).

## Drugs used to treat pain.

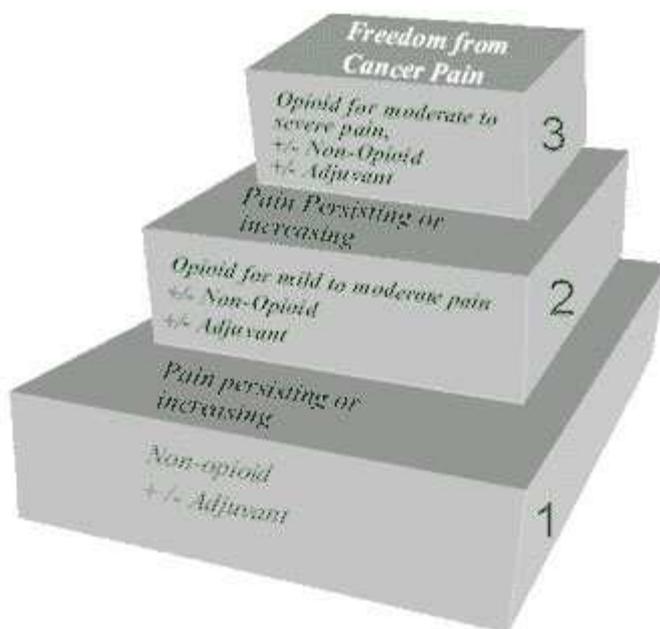
Drugs used to treat pain (analgesics) work in different ways some work directly at the source of pain such as Paracetamol for headaches and some work indirectly such as Gabapentin.

The other group of medications to treat pain are known as Opioids such as codeine or morphine.

The individual's doctor will carefully plan a regime of pain management ensuring that levels pain relief used are appropriate for the individual's level of pain. Below is a diagram showing how pain relief medication may step up in line with increasing pain.

(The W.H.O Pain Relief Ladder, [www.who.int](http://www.who.int) accessed March 2011)

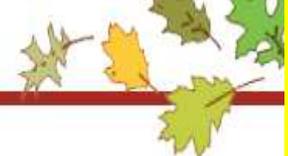
### WHO's Pain Relief Ladder



### Side effects:

There are 3 common side effects of pain medication, the nurse or GP can advise on treatments to help with these side effects.

Drowsiness	Usually wears off a few days after starting the medication.
Sickness	Gradually this should ease off after a few days but you can have an anti sickness drug to take away these effects.
Constipation	Most people need to take a laxative when on pain medication to relieve this symptom.



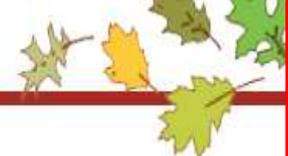
## Anticipatory Prescribing.

As an individual approaches the last few days of life, there may be a need for different medications to be available 'just in case' to ensure the individual is comfortable and pain free during this time. The need for this medication may arise outside of the 'normal' operating hours of a Gp practise but the individual may not want or need a hospital admission. Anticipatory prescribing allows medication to be prescribed before it is needed but to be kept in the home ready for when the time of need may come. The use of this medication will be assessed and managed by the health professionals involved.

Symptom	medication
Agitation/delirium	Levomepromazine and/or Midazolam
Breathlessness	Morphine and/or Midazolam
Nausea or vomiting	<i>Cause known</i> - Cyclizine or Metroclopramide or Haloperidol <i>Cause unknown</i> - Levomepromazine
Pain	Morphine
Respiratory tract secretions	Hyoscine butylbromide

All medication should be reviewed on a regular basis and under no circumstances should alternations be made without the consent of the prescribing doctor or nurse.

Once medications are no longer required they should be taken to a pharmacy to be dispensed of in a safe manner. Some drugs will need to be checked and receipted by the pharmacist.



# Prognosis Less than 1 week

## Nearing the end of a individual's life

The last days and hours of an individual's life can be a scary time for all involved regardless if the individual has a learning disability or not. It may a time for some when 'reality hits' that a person they care for will not be around for much longer or a friend they spend time with will not be there anymore.

This section aims to answer some of the questions that may arise during this time and/or prepare family or paid carers on what may happen during these last days and hours.

## Last days and hours for the person

During this time the individual's body and internal system will slowly be closing down and the organs performing their function will be less and less.

As an individual approaches the end of their life some physical changes will occur, such as;

- Circulation slows, fingers, toes and nose may become cold and change colour.
- Breathing pattern will change, may 'rattle', breathing slows down or becomes uneven.
- Fluid and dietary intake will be very little or none.
- Confusion may occur.
- Anxiety and behavioural changes may be present.

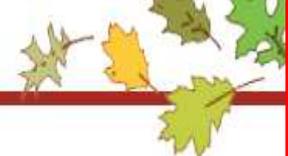
## Liverpool Care Pathway (LCP)

The LCP is a nationally recognised tool of best practice that aims to improve the care of the dying in the last hours or days of life. It was developed to transfer the ethos of hospice care into other care settings such as; the individual's home, care home or hospital ward.

The LCP promotes continuous assessment, planning, management and evaluation of physical, psychological, spiritual and social care.

Good communication underpins the use of the LCP, and it is important to assess the understanding of both the individual and their loved ones regarding what is happening. Any specific communication needs should also be identified and addressed.

To assist professionals in caring for the person who is dying, symptom control guidelines are also provided as part of the LCP. The LCP is a multidisciplinary document.



## Things that may help

Caring for an individual in their last days and hours can be distressing and emotional; the steps outlined below may help those involved in supporting the individual.

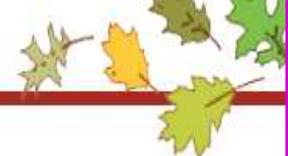
- Keep a contact sheet containing all the telephone numbers of people you may need to contact. (Please use Contact Sheet included in this section)
- Obtain an explanatory letter from the GP; this may help if out of hours services need to be contacted.
- Be fully aware of any Advance Care Plans in situ, i.e. Do Not Attempt CPR.
- Have regular team meetings and give support staff time and opportunity to discuss their own fears and concerns.
- Reminisce good times that involve the individual, listen to their favourite music or watch their favourite TV programme.
- Spend quality time with the individual.

## Last days and hours for others

Everyone responds differently during the last days and hours of the life of an individual we care for, there is no right or wrong answer to reactions of coping in this situation. Some people may;

- Cry and display emotions.
- Want to talk.
- Prefer their own space.
- Feel helpless and unable to function within their role.
- Need to act or do something.

Remember, try not to panic, it will be a distressing situation for all, don't feel as though you can't be upset but don't worry if the tears don't come and adrenalin take over.



## When a friend or family member dies

It is normal to have a variety of emotions after death and different people handle things in different ways. There is no time scale for what an individual should feel and when. It may be that an individual has strong emotions immediately after death of a loved one, but many individuals do not experience these emotions until much later on. Some individuals feel 'anticipatory grieving' where they have strong feelings such as loss and grief before the end of life.

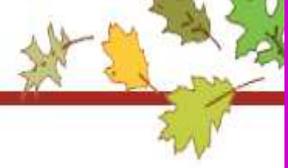
An individual may want to share their feelings with family and friends, but equally, they may not feel comfortable doing this. Some people find it easy to talk to a particular individual – to express their thoughts and feelings freely.

This is no different for someone with a learning disability. Historically it's been believed that someone with a learning disability would not be able to understand or express grief. Therefore some family and staff members have not discussed the death of a family member or friend to someone with a learning disability to try and protect them and so as not to hurt their feelings.

(ref: Blackman N Todd S, Caring for people with Learning Disabilities who are dying (2005) Worth Publishing.

### **How to support an individual with a Learning Disability:**

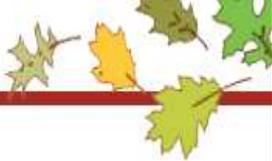
- Be Honest, be prepared to sit and talk to people (including those with no verbal communication) and use methods of communication most appropriate for the individuals (language, photo's, books)
- Remember it's normal to feel unhappy/sad and hurt but be aware that the individual may need time for these feeling to manifest
- Help the individual to think back on positive and enjoyable times 'Do you remember the time that .....?'
- Someone with a Learning Disability may need more than one conversation to fully understand and accept what's happened.
- If you feel sad and upset don't hide this, this will help the individual with a learning disability realise this is a normal reaction to grief.
- Ensure the individual has support to continue with their normal daily lives whilst trying to adapt to living without their friend/family member around them (if this is something they want to continue with)
- Support the person to buy flowers, attend the funeral
- Make a memory box or photo album about the individual to help remember the good & bad times.



## What to do when someone dies

This list may help to guide you when someone you care for dies, it may act as a reminder of who to contact and what may need to happen. *Most care homes will have their own protocol to follow and you should also find this an essential document in supporting you through.*

<i>Action</i>	<i>Time</i>	<i>Date</i>	<i>Name</i>
Check the person has died			
Take a note of the time for written records. Registered Nurses are not required to certify death, they only need to document the facts, the time it occurred and who was present.			
Inform the GP or OOH so the death can be certified			
The doctor who certified death should provide a death certificate within the following few days after death. <b>Check local policy</b>			
Consider if any person (s) would want to say their goodbyes.			
Contact any significant others (friends/family)			
Inform any other residents (see purple section for further support)			
Inform any close staff members			
Contact the undertaker			
Register the death at the local registrars			



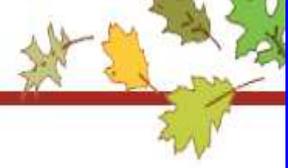
---

# Supporting the pathway

## Appendices

This section includes all the supporting documents and information that may be required, as outlined within the previous sections.

- Appendix 1** Telephone Contact Chart
- Appendix 2** Person Centred Thinking Diagram
- Appendix 3** Learning Disability Services
- Appendix 4** Accessible resources
- Appendix 5** Professional Resources
- Appendix 6** Abbreviations

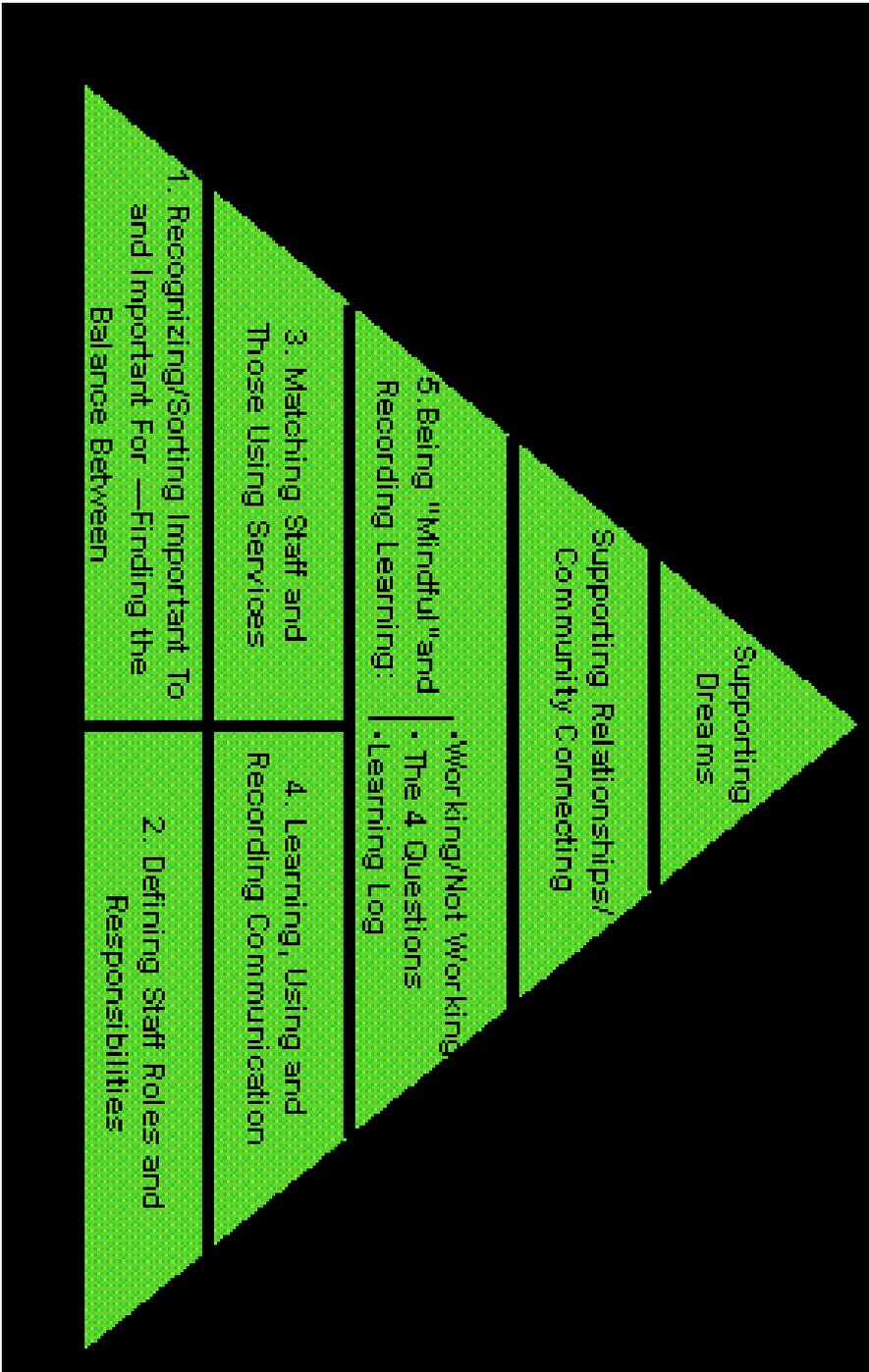


## Telephone Contacts:

(Remove insert and display clearly near a telephone)

<b>Service</b>	<b>Telephone Number</b>	<b>Contact Name</b> (if applicable)
GP		
Out of hours GP		
District Nurse		
Out of hours DN		
Specialist Nurse		
Hospice		
Community Learning Disability Team		

# Person Centred Thinking Diagram



# Directory of Services

## Learning Disability Health Facilitators

Nottinghamshire County:

Department	Description of Services	Admission Criteria	Telephone Contact
Health Facilitator. Newark and Sherwood. Newark Health Centre, Newark	Health Facilitation Team are learning disability nurses who work across primary care. The team provide support to adults with learning disability, carers and professionals, to understand, maintain and improve their physical and mental health needs, whilst reducing identified health inequalities.	Adults with learning disabilities accessing primary care services.	Marie McGahey Strategic Lead – Learning Disability  Central referral line  01636 652620
Nottingham East Park House Carlton			Maureen Major
Nottingham West and Principia Stapleford Care Centre, Stapleford			Ruth Harrison
Mansfield and Ashfield Bull Farm Primary Care Centre, Mansfield			Gemma Del Toro

Nottingham City:

Department	Description of Services	Admission Criteria	Telephone Contact
Health Facilitation Team  New Brook House 385 Alfreton Road, Nottingham, Nottinghamshire, NG7 5LR	Health Facilitation Team are learning disability nurses who work across primary care. The team provide support to adults with learning disability, carers and professionals, to understand, maintain and improve their physical and mental health needs, whilst reducing identified health inequalities.	Adults with learning disabilities accessing primary care services.	Jacqueline Williamson  Sally Henderson  0115 8834859

### Learning Disability Acute Liaison Nurses:

Department	Description of Services	Admission Criteria	Telephone Contact
<p>Learning Disability Nurse Specialist Office 11 Emergency Care Centre, King's Mill Hospital, Mansfield Road, Nottinghamshire NG17 4JL</p> <p>01623 622515</p>	<p>Collaboration with the acute hospital to enable open &amp; easy access to health care services for people with learning disabilities.</p>	<p>Adults with learning disabilities, using any clinics, theatres or inpatient facilities at either the King's Mill Hospital or Newark Hospital site.</p>	<p>Claire Henley</p> <p>01623 622515 Ext 6091</p> <p>Claire.henley@sfh-tr.nhs.uk</p>
<p>Acute Liaison Nurses St Francis Unit Nottingham City Hospital, Hucknall road, Nottingham, NG5 1PB</p> <p>0115 969 1169</p>	<p>Collaboration with the acute hospital to enable open &amp; easy access to health care services for people with learning disabilities.</p>	<p>Adults with learning disabilities, using any clinics, theatres or inpatient facilities at either the QMC or City site.</p>	<p>Senior Acute Liaison Nurse George Badiali 0115 969 1169 ext: 56568</p> <p>ALLDT@nottshc.nhs.uk</p>
<p>Acute Liaison Nurse Bassetlaw Hospital Blyth Road Worksop Nottinghamshire S81 0BD</p>	<p>Collaboration with the acute hospital to enable open &amp; easy access to health care services for people with learning disabilities.</p>	<p>Adults with learning disabilities, using any clinics, theatres or inpatient facilities at Bassetlaw Hospital.</p>	<p>Michelle Neal 01909 502933 07827 929642</p> <p>Michelle.neal@nottshc.nhs.uk</p>

### Community Learning Disability Teams (CLDTs)

Department	Description of Services	Admission Criteria	Telephone Contact
<b>County CLDTs</b>			<b>Michelle Handsaker</b>
<p>Ashfield CLDT 68 Portland Street Kirkby in Ashfield Mansfield Nottinghamshire NG17 7AG</p> <p> 01623 785473</p> <p> 01623 785453</p>	<ul style="list-style-type: none"> <li>Multi-disciplinary and multi-agency teams</li> <li>Includes a range of professionals: Consultant Psychiatrists, Occupational Therapists, physiotherapists, Learning Disability Nurses, Social Workers, Welfare Rights Officers, Speech and Language Therapists and Clinical Psychologists.</li> <li>Gate-keeper to needs led services.</li> <li>Transition service for clients aged 16 – 18 available.</li> </ul>	<ul style="list-style-type: none"> <li><b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li><b>Level:</b> Varying degrees of learning disability.</li> <li><b>Area:</b> Living in the Ashfield Community.</li> </ul>	<p>Integrated Team Manager Andy Bigger 01623 785473</p> <p>Professional lead community nurses Deborah Yates 01623404614 07880711921</p>

## County CLDTs

Department	Description of Services	Admission Criteria	Telephone Contact
<p>Bassetlaw CLDT Queens Building Potter Street Worksop S80 2BZ</p>  <p>01909 535565 Fax 01909 535603</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Bassetlaw Community.</li> </ul>	<p>Integrated Team Manager Brian Hunt 01909 535565</p> <p>Professional lead community nurses Deborah Yates 01623404614 07880711921</p>
<p>Broxtowe CLDT Sunnyside Road Beeston Nottingham NG9 4FR</p>  <p>0115 943 1086 Fax 0115 957 5356</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Broxtowe Community.</li> </ul>	<p>Integrated Team Leader Jo McAuley 0115 943 1086</p> <p>Professional lead Community Nurses Bridget Smart 0115 854 2233</p>
<p>Gedling CLDT Sir John Robinson Way Arnold Nottinghamshire NG5 6DB</p>  <p>0115 854 6230 Fax 0115 854 6209</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Gedling community.</li> </ul>	<p>Integrated Team Leader Paul Jackson 0115 854 6230</p> <p>Professional lead community nurses Deborah Yates 01623404614 07880711921</p>
<p>Mansfield CLDT Chadburn House Weighbridge Road Mansfield Nottinghamshire NG18 1AH</p>  <p>01623 436640 Fax 01623 436651</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Mansfield community only.</li> </ul>	<p>Integrated Team Leader Sue Jaycock 01623 436640</p> <p>Professional lead community nurses Deborah Yates 01623404614 07880711921</p>
<p>Newark CLDT Byron House Boundary Road Newark Nottinghamshire NG24 4DE</p>  <p>01636 685927 Fax 01636 685926</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Newark &amp; Sherwood Community</li> </ul>	<p>Integrated Team Leader 01636 685927</p> <p>Professional lead community nurses Deborah Yates 01623404614 07880711921</p>

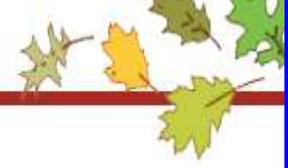
## County CLDTs

Department	Description of Services	Admission Criteria	Telephone Contact
<p>Rushcliffe CLDT West Bridgford House Loughborough Road West Bridgford Nottingham NG2 7UN</p>  <p>0115 8783579 Fax 0115 8465652</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+ (With the exception of the Transition Service)</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Rushcliffe community.</li> </ul>	<p>Integrated Service Team Manager Alison Jackson 0115 878 3579</p>

## City CLDTs

Department	Description of Services	Admission Criteria	Telephone Contact
<p>Nottingham East CLDT Mary Potter Centre Gregory Boulevard Hyson Green Nottingham NG8 3DH</p>  <p>0115 915 2468/9 Fax 0115 883 8555</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the city's community.</li> </ul>	<p>Team Leader Nikki Young 0115 883 9962</p> <p>Professional lead Community Nurses Bridget Smart 0115 854 2233</p>
<p>Nottingham City North CLDT Denewood Centre Denewood Crescent Bilborough Nottingham NG8 3DH</p>  <p>0115 915 9638 Fax 0115 915 9618</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the city's community.</li> </ul>	<p>Integrated Team Leader Maureen Downes 0115 915 96386</p> <p>Professional lead Community Nurses Bridget Smart 0115 854 2233</p>
<p>Nottingham City South CLDT Corner Stone South Church Drive Clifton Nottingham NG11 8EW</p>  <p>0115 943 1086 Fax 0115 878 6377</p>	As above	<ul style="list-style-type: none"> <li>• <b>Age:</b> 18+</li> <li>• <b>Level:</b> Varying degrees of learning disability.</li> <li>• <b>Area:</b> Living in the Clifton community.</li> </ul>	<p>Professional lead Community Nurses Bridget Smart 0115 854 2233</p>

A full service directory can be downloaded from  
[www.nottinghamshirelearningdisabilitypartnershipboard.org](http://www.nottinghamshirelearningdisabilitypartnershipboard.org)



## Accessible Resources

### **'About my friend: for friends of people with Down's syndrome and dementia'** (IP)

Karen Dodd, Vicky Turk and Michelle Christmas

A picture booklet that outlines the dementia process and helps people with a learning disability understand what happens when a friend gets dementia.

Further information available at [www.bild.org.uk](http://www.bild.org.uk)

### **'Belly Ache'** (IP)

Speak up Self Advocacy

Accessible DVD for people with learning disabilities discussing gastro-intestinal cancer.

Further information available at [www.friendlyinformation.org.uk](http://www.friendlyinformation.org.uk)

### **'Books Beyond Words'** (IP)

- **Am I going to die?**
- **Getting on with Cancer**
- **When Dad died**
- **When Mum died**
- **When somebody dies**
- **Going to the doctor**
- **Going to outpatients**
- **Going into hospital**

Royal College of Psychiatrists

A series of picture books developed for individuals with a learning disability.

Further information available at [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

### **'Coping with Death'** (IP)

Speak up Self Advocacy

This film shows a funeral and how to cope when someone a person cares for has died. It also helps a person to think about death.

Further information available at [www.friendlyinformation.org.uk](http://www.friendlyinformation.org.uk)

### **'Death by Indifference' (easier read)**

Mencap (2007)

A report of institutional discrimination within the NHS and individuals with a learning disability receiving poor healthcare.

Free to download from [www.mencap.org.uk](http://www.mencap.org.uk)

### **'Decisions, Decisions'** (IP)

A board game and accessible DVD for people with learning disabilities about the Mental Capacity Act produced by Speak Up Self Advocacy Group.

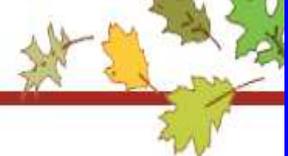
Further information at [www.friendlyinformation.org.uk](http://www.friendlyinformation.org.uk)

### **'Going into hospital'** (IP)

Speak up Self Advocacy

This film is all about going into hospital.

Further information available at [www.friendlyinformation.org.uk](http://www.friendlyinformation.org.uk)



**'Let's Talk About Death' (IP)**

Karen Watchman (2004)

A booklet discussing funerals and death, also accompanied by an audio cassette.

Further information available at [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

**'Living with an illness that I may die from' (IP)**

Palliative Care and People with Learning Disabilities (2009)

A series of information leaflets for individuals with a learning disability.

Available free from [s.c.read@nur.keele.ac.uk](mailto:s.c.read@nur.keele.ac.uk)

**'Living with cancer' series'**

FAIR Multimedia

Illustrated series of booklets discussing cancer and the relating issues.

Further information available at [www.fairadvice.org.uk](http://www.fairadvice.org.uk)

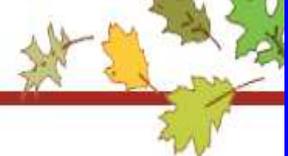
**'Making a Will'**

Speak up Self Advocacy

This film for people with learning disabilities that helps a person think about what may happen to their money and possessions after they die.

Further information available at [www.friendlyinformation.org.uk](http://www.friendlyinformation.org.uk)

**(IP) = Resource available via an Information Prescription either free or on a loan basis**



## Carer and Professionals Resources

### **'Advice for Hospitals and Health Professionals'**

Mencap (2008)

Tips for healthcare professionals when caring for a person with a learning disability.

Free to download from [www.mencap.org.uk](http://www.mencap.org.uk)

### **'An Ordinary Death'**

The Foundation for People with Learning Disabilities (February 2003)

[www.fpld.org.uk](http://www.fpld.org.uk)

### **'Cancer and People with Learning Disabilities'**

James Hogg, John Northfield and John Turnbull (2001)

A report commissioned by the Department of Health.

Order online from [www.bild.org.uk](http://www.bild.org.uk)

### **'Caring for People with Learning Disabilities who are dying'**

Noelle Blackman and Stuart Todd (2005)

Raises the awareness of everyone involved in enabling people with learning disabilities to be treated with respect and dignity as they approach death.

### **'Death by Indifference'**

Mencap (2007)

A report of institutional discrimination within the NHS and individuals with a learning disability receiving poor healthcare.

Free to download from [www.mencap.org.uk](http://www.mencap.org.uk)

### **'Dying Matters'**

The Foundation for People with Learning Disabilities ((March 2005)

A workbook for staff supporting people with learning disabilities.

Order online from [www.fpld.org.uk](http://www.fpld.org.uk)

### **'Equal Treatment: Closing the Gap'**

Disability Rights Commission (2006)

A report of the formal investigation into physical health inequalities experienced by individuals with a learning disability.

Free to download part 1 from [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

### **'Feeling Better'** (IP)

Dr Sharon McManus and Dr Brian McGuire

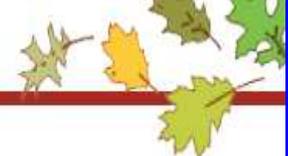
This resource pack is designed to provide practical guidance for health workers who work with people who have learning disabilities and chronic pain, includes a DVD.

[www.pavpub.com](http://www.pavpub.com)

### **'Living with Learning Disabilities, Dying with Cancer'** (IP)

Irene Tuffrey-Wijne (2009)

Thirteen Personal Stories



**'Loss and Learning Disability'**

Noelle Blackman (2003)

Addresses how people with learning disabilities may be affected by the loss of a loved one.

**'Treat me right! Better healthcare for people with a learning disability.'**

Mencap (2004)

A report calling for better health care provision for individuals with a learning disability.

Free to download at [www.mencap.org.uk](http://www.mencap.org.uk)

**'Valuing People. A New Strategy for Disability for the 21<sup>st</sup> Century.'**

Department of Health (2001)

This is the first White Paper on learning disability for thirty years and sets out an ambitious and challenging programme of action for improving services

Free to download at [www.dh.gov.uk](http://www.dh.gov.uk)

**'Valuing People Now. A New 3 Year Strategy for People with Learning Disabilities'**

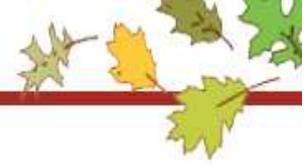
Department of Health (2008)

Valuing People Now sets out the Government's strategy for people with learning disabilities for the next three years following consultation.

Free to download at [www.dh.gov.uk](http://www.dh.gov.uk)

**(IP) = Resource available via an Information Prescription either free or on a loan basis.**

The resources listed are just a selection of those available.



## Abbreviations:

ACP	Advance Care Plan
ADRT	Advanced Decision to Refuse Treatment
CHC	Continuing Health Care
CLDT	Community Learning Disability Team
DNAR	Do Not Attempt Resuscitation
EMAS	East Midlands Ambulance Service
EoL	End of Life
GP	General Practitioner
HAP	Health Action Plan
HTLA	Hospital Traffic Light Assessment
LCP	Liverpool Care Pathway
LD	Learning Disability
MDT	Multi-disciplinary team
NHSD	NHS Direct
OOH	Out of Hours
PCP	Person Centred Plan
PPC	Preferred Priorities of Care
SPC	Specialist Palliative Care



## Notes

