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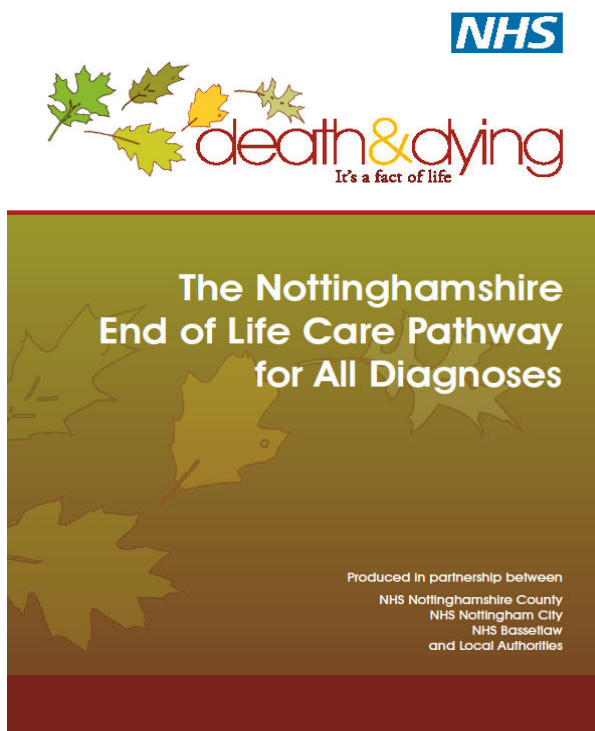
# Improving End of Life Care for People with Learning Disabilities

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*Sherwood Forest Hospitals Foundation Trust.*

Gemma Del Toro, Learning Disability Health Facilitator,  
*Mansfield and Ashfield, Nottinghamshire Healthcare Trust.*

# Nottinghamshire End of Life Care Pathway for ALL Diagnoses

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*"Good communication is the cornerstone of a joined up service, this pathway has been developed to ensure that local health & social care services work together to ensure patients wishes are realised."*



## Background

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Evidence suggests that people with learning disabilities do not have equal access to healthcare, this includes end of life care. End of life care is a national target area for improvement.

*“ We are a Learning Disability Home, we don’t do end of life care!.”*

A worker

A decorative graphic on the left side of the slide, consisting of two overlapping semi-circles. The top one is a darker orange-red, and the bottom one is a lighter orange-gold.

# Working Party.....

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- Therefore a decision was made to form a working party in Nottinghamshire to look at how we ensure people with learning disabilities receive inclusive end of life care.
- An initial meeting took place on 15th June 2010 to look at how this process would start. The group consisted of professionals from Public Health, End of Life Care services, secondary care, and learning disability professionals. The group reviewed *'Mencap – Living and dying with dignity, best practice guide'* and looked at the 12 main messages. These would help to inform the group of which areas are a priority.
- Funding and support for the project from the National End of Life Care Programme



# Mencap's 12 key messages are...

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**1. People with a learning disability often experience barriers to end-of-life care and support. Professionals should be aware of these barriers and try to overcome them.**

2. Carers should talk openly and honestly about all aspects of death and dying while the people they support are well and healthy.

**3. Communication is the key to effective end-of-life care and support.**

4. Carers should encourage the people they support to look for changes in their bodies and help them to be aware of the importance of health and wellbeing clinics, classes or groups.

**5. Carers should ensure they identify any changes in the health status of the person they support, seeking professional advice where appropriate.**

6. Talking to family and friends, and working with familiar carers, provides a clearer picture of the person and promotes holistic care.

**7. Preparing the patient for diagnostic procedures and tests is very important. It takes time, creativity and forward planning.**

8. Breaking difficult news should be done by familiar carers – they must be guided by the person receiving the news and carers should avoid creating unrealistic expectations.

**9. All people involved in a person's life will need variable support both when the person dies and afterwards.**

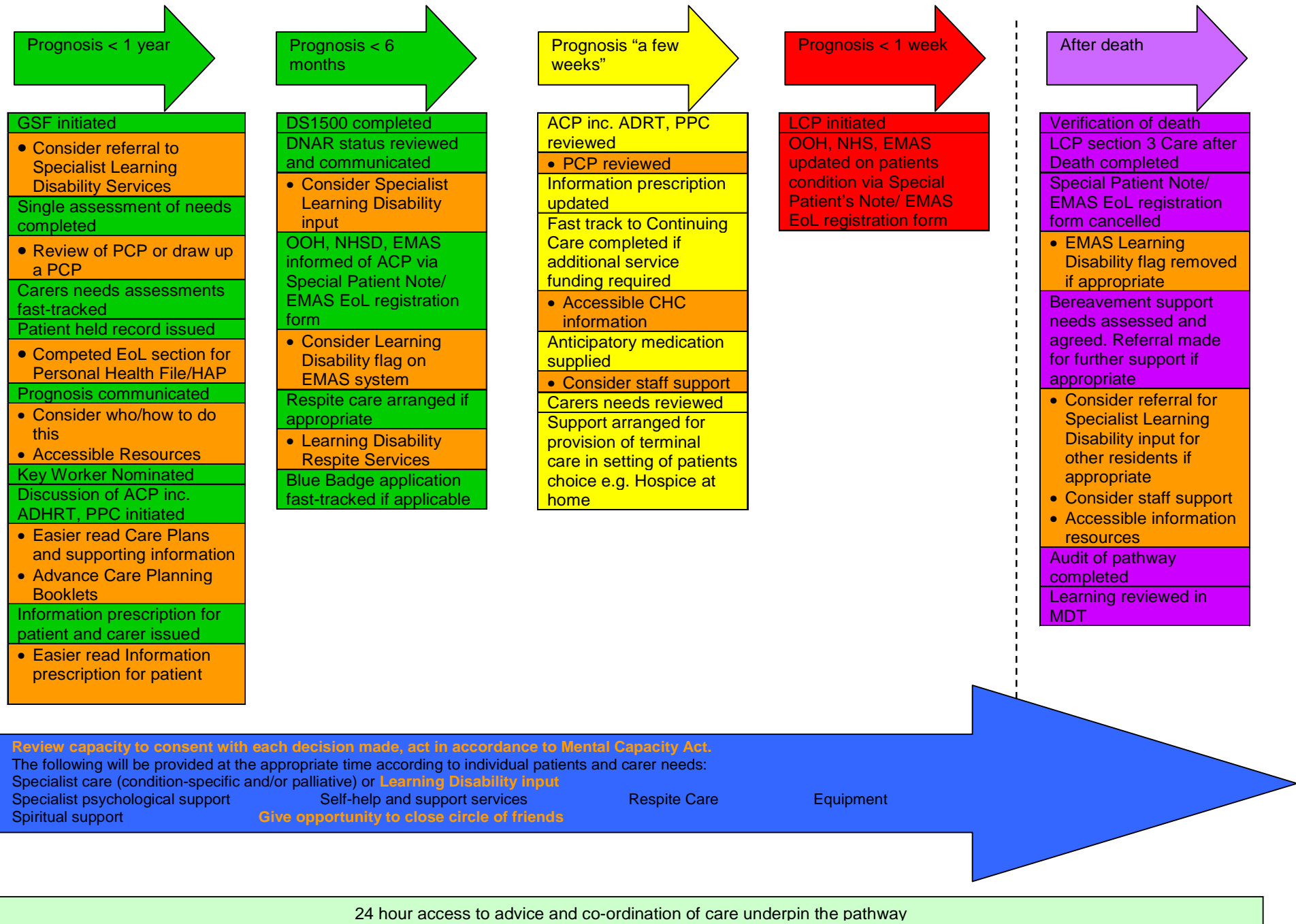
10. People with a learning disability must be treated with respect and dignity, and treated as an adult throughout their illness.

**11. End-of-life care and support is delivered by many different people. Professionals must ensure they work together effectively.**

12. Every person involved in end-of-life care must always do their very best to give every person with a learning disability the support they deserve and need.

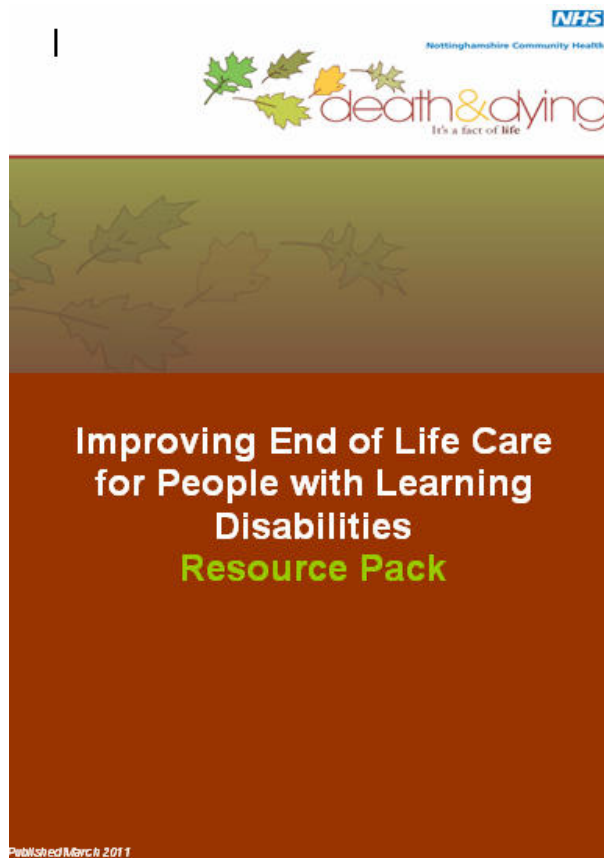


# Learning Disability End of Life Care Pathway – Details of Care Provision




# Resource Pack

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A Resource pack that supports the pathway by providing information and signposts services.


# Information Prescription







**i** My Information Plan

This plan is for:  
NHS No:

 This information is to help you understand what is happening to you.

 It will help you decide what you want.

 My Health Key Worker is:	 Telephone number:	 Times they can be contacted:

 Other people supporting me can be found in my Personal Health Profile.

Developed by:  
Claire Henney, Sherwood Forest Hospitals Foundation NHS Trust,  
Gemma Del Toro, Nottinghamshire Community Health NHS Trust  
February 2011  
Adapted from: Nottingham City PCT, Information Prescription

- Information prescriptions can be requested in 2 ways.
- Central resource library.
- Information available in a variety of formats.
- An area of continual development.

Information Prescriptions for Learning Disabilities [Change](#)

[A+](#) [A-](#)



### Welcome to your personalised information prescription

This information prescription covers End-of-Life. It is intended for a female patient aged 18-25 from Ashfield (inc Hucknall). [Change](#)

To make the information within your prescription manageable it is divided in to sections on the right.

- Information is grouped in to sections
- You can choose to [print](#) or [download](#) some or all of this information prescription by clicking the print or download buttons at the bottom of the page.

#### Sections

- [My Future Care](#)
- [End of my life](#)
- [After my death](#)
- [Other things I have information on](#)
- [My Needs](#)
- [My Care](#)

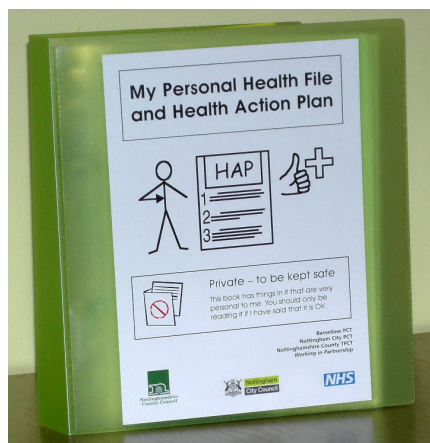
[You can choose exactly which sections of this information prescription you wish to Print](#)

[If you prefer you can download sections of this information prescription as a PDF Download](#)

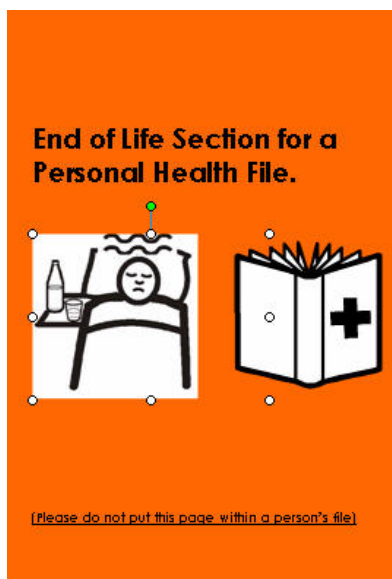
[We hope you found this site useful.](#)

[Please tell us what you found helpful and why and help us to make good great!](#)

# End of Life section for a Personal Health File.



Given by the person's GP once initiated on the 'End of Life' pathway.



# Other tools

NHS Number: \_\_\_\_\_ **NHS**

## My Pain Profile



You can stick your own photograph here if you wish. \_\_\_\_\_

**This belongs to** \_\_\_\_\_

Someone who knows me well is \_\_\_\_\_ and they can be contacted on \_\_\_\_\_.

© Acknowledgements to: Somerset Total Communications, Simple Symbols, Gemma Del Toro, Community Learning Nurse, October 2009

**NHS**

## Preferred Priorities of Care (Accessible Version)



# Service user involvement

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# Making them think!

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- GP awareness
- Posters
- Resource pack
- Data analysis

# Training events

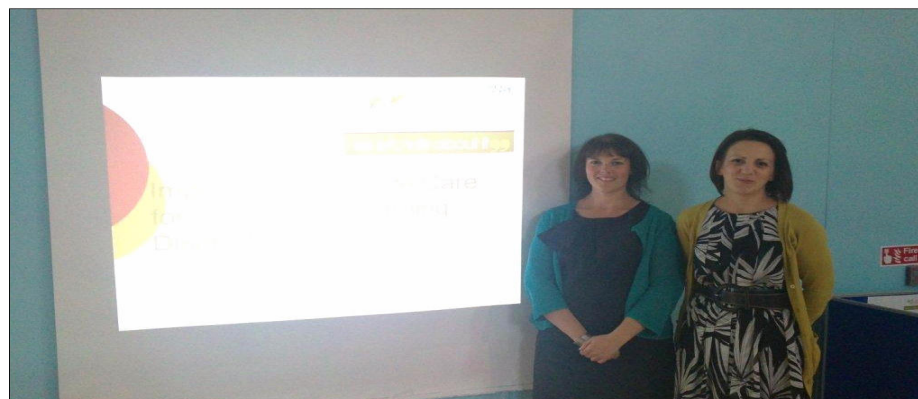
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Learning Disability home manager – ***"A very good enjoyable day, good amount of information given. Really enjoyed the drama group after lunch, a big well done to them"***.

Palliative carer – ***"Very informative day, I am now able to help much more and know where to go to get the support"***

Acting care manager in nursing home – ***"Enjoyed learning different communication skills/tools used in Learning disabilities this increased my knowledge"***.

Short breaks manager – ***"very informative day, good group discussions"***





# Benefits

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- Improve awareness
- Improved support for mainstream professionals
- Improved care during End of Life.
- Access to information improves their own awareness of what is happening and aids decision making/having a choice.
- Decrease emergency admissions to hospital
- Improved advanced planning
- Improved communication and joint working.
- Increased confidence of Support staff in providing care to an individual at End of Life



## Future

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- Further training for Primary and Secondary Care staff.
- Further awareness raising on initiating pathway by medical professionals.
- Further training events.
- Evaluation of project.



# **What are the thoughts and feelings of people with learning disabilities about end of life?**

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# Thank you.

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“let's talk about it”

## With everyone!

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