

## 'MY END OF LIFE PLAN' – GUIDELINES FOR SUPPORT

This document aims to give guidance and provoke thoughts and ideas, when supporting a person to think about the end of their life.

The subject of illness, death and thinking ahead must be approached with sensitivity and knowledge of the person's background and cultural beliefs.

We should seek to use every resource at our disposal, including professional advice, communication aids, information already documented about the person's preferences, likes and dislikes and information obtained from family and others who are important to that person.

A multi – disciplinary approach to gathering information is essential when acting in the best interest of someone who has communication difficulties. It is vital to remember that each person is an individual. In doing so, it will be necessary to plan around the persons preferred method of communication, how they receive and understand information and their current experiences and knowledge of death.

Where the person is not able to give informed consent to the development of their 'End of Life Plan', the 'Best Interest' route should be followed.

Throughout 'My End of Life Plan' you will see gaps where photographs may be added, both to aid understanding and to re-enforce ownership of the document.

Where photos, pictures and symbols already exist within the document, they can be used to prompt the person during communications, but may also be replaced with drawings, symbols or other photos depending on the person's preferred method of communication.

Thinking about all the issues that are covered in 'My End of Life Plan', can evoke lots of feelings, both for the person and for those who are supporting them.

It is therefore vital to approach this sensitively, whilst acknowledging your own experiences and feelings around illness and death.

There will undoubtedly be people who simply don't want to contemplate thinking about planning for the end of their life. Past experiences may affect the way the person feels and expresses themselves on the subject.

It is therefore vital that you know the person well; have a good rapport with them and are aware of any anxieties they have around getting older and nearing the end of life.

If a multi-disciplinary group come to the conclusion that it would be inappropriate to broach the subject of end of life planning with the person, it may be more appropriate to explore developing a **life history or life plan**, where important events and information could be recorded. This may then lead to the person being able to look forward and make plans for later life. Some of the resources listed on pages 5 & 6 of this document may be of use.

This document aims to cover all aspects of helping a person make choices around planning for the end of their life. It should be emphasised that any work done around gathering information, should be carried out at a pace to suit the person you are supporting. In short, the work should be on-going and reviewed when appropriate.

'My End of Life Plan' is not a resource that everybody will be able to use in its present form. As with all resources, it will suit some people, but not others. Feel free to adapt it.

- Those people with more profound disabilities may not be able to make **all** their wishes known to us. However, it should never be assumed that where communication differences occur between the person and the facilitator, the person is not able to make choices. It is therefore vital to ensure that information is presented in a way that is meaningful and offers the person the best opportunity to understand.

'My End of Life Plan' can contain as much, or as little information as the person wants, or wishes to share.

### **Page 2, 3**

When approaching the subject of 'making a will' or reviewing one already in existence please refer to your organisations Policy Document/Care plan for supporting a person with a life-threatening/terminal illness.

### **Pages 4, 5**

When gathering information about belongings and people who are important to the person, the use of photographs is particularly important.

It may also be useful to consider those people who were once part of the person's life i.e. friends from a previous home or ex- staff members.

### **Page 6,7,8,9**

The subject of 'where I want to be when I die' needs careful thought and consideration.

It is important to remember that should the person be diagnosed with a life-threatening or terminal illness, the subject of 'where I want to be when I die' may need to be re-visited, in the light of circumstances which may affect the person's wishes.

### **Page 10**

This page could be used to record where the person would like their belongings to go, after their death e.g. if they would like certain items to be buried with them as a memento or for those belongings to go to family or friends or a charity etc.

### **Page 11, 12, 13**

It should be remembered that there are rules and regulations pertaining to religious establishments/ organisations and differing cultures, which may affect the person's choice of burial site and service.

For example, a cemetery of the person's choice may be full; the person's religion may impinge upon their choice; some churches have catchment areas and rules around a person's place of birth etc; the person may choose to be buried with family but there is no room in the plot; there may already be a family plot but the family are against the person being buried there.

There are non – religious places of burial if people so choose. The internet can be a good source of information.

**It is important to realise that cost may have big implications when planning for a funeral and it may not be possible for the person to have everything they want.**

**Different religions and cultures have rules and customs which must be respected. It is vital to be aware of these before embarking on planning with the person.**

### **Page 14, 15**

Where a person has indicated a preference to have their Ashes scattered rather than buried, it is important to check with local Authorities about any rules and regulations in place.

### **Page 16**

The person may indicate a named person to read a poem/ something from the Bible/ a funny story about the person's life etc.

They may want a traditional/ non- traditional service

They may indicate a wish for example that everyone wears black, or that nobody wears black.

The person may only want close friends at the service etc.

The person may indicate a wish for certain close friends or family to carry the coffin.

### **Page 17, 18, 19, 20, 21**

If the person has family who wish to have input to the process it should be remembered that the views and wishes of those family members may not necessarily be the same as the views and wishes of the person you are supporting.

Whilst it is important to involve the family (if the person does not disagree), our role is to support the **person** to have **their** wishes carried out.

### **Page 22, 23, 24**

This page is for making known the person's wishes around 'After the funeral service' i.e.

Do the mourners meet up after the service?

Where would this happen/ at the person's home or elsewhere?

Would it be a small gathering or more of a party?

How would the person want their life commemorated? E.g. planting of tree/flowers in the garden/ visiting the grave regularly with flowers etc.

Throughout the process of supporting the person to develop their 'End of Life Plan', the '**Record of Communication**' Sheets should be used to accurately document the person's wishes, the resources used, details of multi-disciplinary discussions and the individuals involved in the process. It would be good practice to record during the first multi-disciplinary meeting, the person's preferred method of communication, together with suggestions for how best to share information with the person.

Here are some questions you should consider asking:

- How does the person communicate? I.e. words, gestures, signs, pictures, photos, vocalisations, experiential opportunities etc.
- How can information be presented in a format to aid understanding?
- What known anxieties, if any, does the person have around illness, getting older, death?
- How do we approach the person for consent to support them to develop their end of life plan?
- Do we need to approach medical professionals to inform decision-making and join the multi-disciplinary team?
- Would it be more appropriate to approach Life History planning?
- Who will be involved? Family/Carers?
- What resources can we use?
- Would it be in the person's best interests to gather information towards planning for the end of their life?
- What information do we need to gather?
- Who will do what? Timescales?
- When will next multi-disciplinary meeting be held?

## **Useful Resources and References:**

**'My Health Book' and Health Action Plan Summery.** An A5 Book is a book produced to help keep people with learning disabilities healthy. The book includes documents in an easy read format designed to be used by people with learning disabilities and their carers/health facilitators. The book is intended to be used and updated regularly. It includes 'My Health Assessment' Information for Carers Professionals and Others, Hospital Assessment Document, End of Life Plan, Health Action Plan Summery and lots of other useful resources.

Produced by the Health Facilitation Team, Learning Disability Services, Together NHS Foundation Trust. Tel. Freephone: 0800 019 3346 e.mail: [Simon.shorrick@glos.nhs.uk](mailto:Simon.shorrick@glos.nhs.uk)

**End of Life Care Strategy** – Promoting high quality care for all adult at the end of life. Department of Health, Quality Markers Consultation November 2008

**Living and dying with dignity** – Easy Read - This leaflet tells you what is important about caring for someone with a learning disability when they have a life-limiting illness.

MENCAP – Tel: 01159 827022. [www.mencap.org.uk/endoflifecare](http://www.mencap.org.uk/endoflifecare)

**Supporting People with Disabilities Coping with Grief and Loss** – Easy Read – **Scope**, 830 Whitehorse Road, Box Hill, Melbourne, Australia, 3128

**Liverpool Care Pathway** – [www.lcp-mariecurie.org.uk](http://www.lcp-mariecurie.org.uk)

### **Series of five leaflets:**

**Living with an illness that I will die from** – “The puzzle of palliative care” Palliative care and people with learning disabilities (P.C.L.D) Dr Sue Read, Senior Lecturer, Keele University. Email: [s.cread@nur.keele.ac.uk](mailto:s.cread@nur.keele.ac.uk)

1. Finding out...

2. A Guide for Professionals Offering Palliative Care & Support.

3. What Next...

4. Being Prepared.....

5. A Carers Guide.....

'Someone Has Died' - uses words and symbols as well as both colour and black and white photographs to explain the following: Feelings of loss; someone you know has died; visiting the undertakers; funerals/ burials/ cremations; visiting a grave; what happens when you die. This is available from 'Pluss', Waddeton Close, Nr Brixham Road, Paignton, Devon, TQ4 7RZ Tel. No. 01803 520386.  
Web address: [www.pluss.org.uk](http://www.pluss.org.uk)

'My life, My Plan' – A set of visual materials which can be used to support communication with people with learning difficulties about their lives: where they are now and where they want to be. It aims to help people with communication difficulties to identify and express their own wishes and needs and create their own plans.  
Contact details as above.

'My Life' – A beautifully illustrated A3 booklet in colour, which can be used to support a person, to record important events in their life. This booklet was originally developed for a gentleman suffering from Alzheimer's disease. Although not yet widely available, for information regarding this resource please contact - Sue Bailey, Colliers Court Hospital, Latimer Road, Cinderford, GL14 2QA. Tel. no. 01594 598085.

'The Tree Of Life' – Using the illustrated tree from the front of the 'My Life' booklet, this can be enlarged to again support the person to record important events in their life. The enlargement allows for photos to be used. Contact details, as for 'My Life'

'Talking Together About Death' – A boxed set of cards, illustrated in black and white, depicting objects and scenarios around the circle of life. Available from the 'Winslow Press'  
[www.winslow-press.co.uk](http://www.winslow-press.co.uk)

'Let's Talk About Getting Older' – A booklet illustrated in colour, depicting things that might happen when you get older. Produced by 'Down's Syndrome Scotland' Tel. no. 0131 313 4225. This booklet can be downloaded straight from their website [www.dsscotland.org.uk](http://www.dsscotland.org.uk). This is also available to borrow from the Gloucester Health Facilitation Team Tel. no. 01452 891357.

'Let's Talk About Death' – A booklet illustrated in colour, explaining what happens when a person dies and what happens at a funeral. Produced by 'Down's Syndrome Scotland'.  
Contact details as above.

'What Is Important To You?' - A booklet illustrated in colour and using text, to explain about different life events and how they may be important to a person. This is produced by the 'Foundation for People with Learning Disabilities' and is available from their website [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk).

'Making a Will' – A DVD by the 'Speakup' self advocacy group, which talks about why people make a will and how to go about getting one. Available from 'Speakup' ,31 Broad Street, Rotherham, S62 6DX. Tel. no. 01709 710199. Website address [www.speakup.org](http://www.speakup.org)

'Coping With Death' – A DVD by the 'Speakup' self advocacy group, which talks about what death means to different people; their thoughts, feelings and coping mechanisms. Contact details as above.

'Advance Directive/End of life Care Plan For People with learning Disabilities', by Chloe Cobbold at Cotswold and Cirencester Community learning Disability Team, Chesterton Hall Resource and Information Centre, Meadow Road, Cirencester, GL7 17A. Tel. no. 01285 648530.

'Mayfield Trust Policy Document/Care Plan for supporting a person with a life threatening or terminal illness' by Enfys Groombridge and Vicky Everton– Available from The Brandon Trust, Unit GO1, Kestral Court, Waterwells Business Park, Quedgley, GL2 2AT  
Tel. No. 01452 886307

'When I Die' – A4 booklet where a person can record their wishes around planning for their funeral, comprising photos, drawings and symbols. This document is produced by Calderstones NHS Trust, Mitton Road, Whalley, Clitheroe, Lancs, BB7 9PE. Tel. no. 01254 822121.  
Web address: [www.calderstones.nhs.uk](http://www.calderstones.nhs.uk)

Below is a list of additional staff resources, which could aid information gathering.

Essential Lifestyle Plans; Careplans; Total communication Aids; Advocacy; Health Facilitation Team and their Resource library; Health professionals including G.P, Speech and language therapist, Psychiatrist etc; family; Those people who are important to the person; Care support team; Specialist nurses; Best Interest Procedures document; Consent guidelines; photographs, magazines and catalogues, information from reputable websites, including Department of Health, Citizens Advice, local government, Foundation for People with Learning Disabilities, British Institute Of Learning Disabilities (BILD)

Originator: Julie Crisp  
The Brandon Trust

Edited by: Denise Mellon  
Simon Shorrick  
Health Facilitation Team  
Learning Disability Services  
2gether NHS Foundation Trust

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'My End of Life Plan'

Date:

Name of person:

Date of birth:

Address:

G.P (name, address, phone no.):

Next of kin (name, address, phone no., relationship to person):

The purpose of this document is to record all communications that have taken place, towards the gathering of information for 'My End of Life Plan'.

A separate section, 'Actions to be taken' is included, which may help to focus on the next steps ahead.

It should include details of how 'informed consent' was given and what information was shared with the person, in order to obtain said consent.

If the person was not able to give their consent, this record must give details of multi-disciplinary discussions which took place, in the best interest of the person.

When supporting the person to develop their 'End of Life Plan', please use the 'Guidelines for Support'.

'My End of Life Plan' – RECORD OF COMMUNICATIONS

Date:

Actions to be taken

Signed