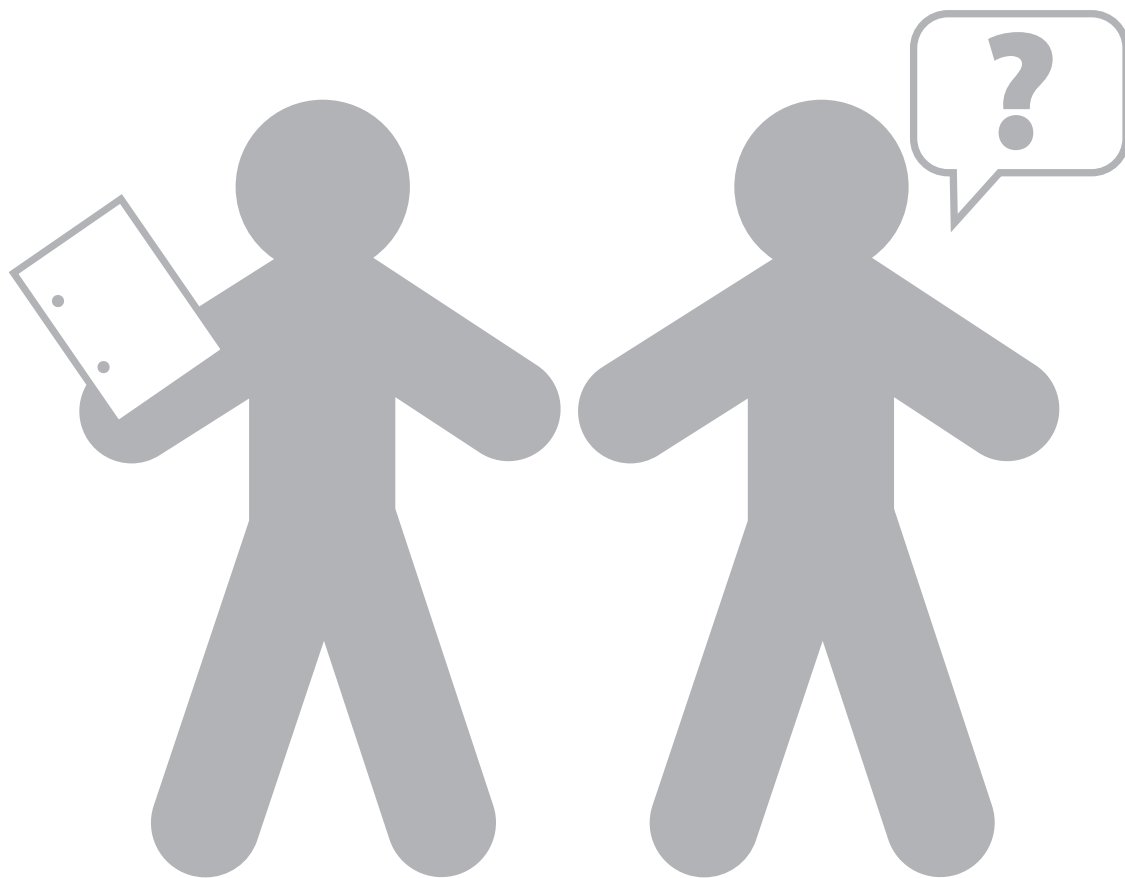




A volunteer training programme about **Advance Care Planning**

# Resource list



## Advance Care Planning (ACP) Resource List

Document	Who is it for	What is it about	Availability NB: Unless stated otherwise; all resources are free of charge.	How to use it Here we give some suggestions of how the resources may be of use as part of or after the training course. If used in the training course, adapt the module plan accordingly.
Capacity, care planning and advance care planning in life limiting illness. A guide for Health and Social Care Staff May 2011	This is an A4 booklet for health and social care staff who may find it useful to use in their day to day practice when preparing to discuss issues about advance care planning with individuals they are supporting/caring for.	This is a useful resource for staff or volunteers to become familiar with the different terms used around advance care planning and how to introduce ACP to individuals they are supporting/caring for. It also sets out information about the legal issues and training needs related to ACP. It provides some examples of the application of ACP.	National End of Life Care Programme  Available to download: <a href="http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide">www.endoflifecareforadults.nhs.uk/publications/pubacpguide</a>	This booklet is quite detailed and can be used as a resource to become more familiar with issues and terms related to ACP. As such it may be a useful resource for training.  It is aimed at a broad audience of generalist staff. It may also be of use to volunteer educators working to raise awareness about ACP  There is a list of background resources staff and volunteers may wish to use to find out more information or to access other resources.
Advance Decisions to Refuse Treatment - A Guide for Health and Social care Professionals Published September 2008	This is an A4 booklet designed to be used by health and social care staff who will already have some understanding about ACP and who require more detailed information about the law relating to ADRT.	This guide deals with advance decisions to refuse treatment at a future date (ADRT) ADRT must meet the requirements of the Mental Capacity Act to be legally binding and the guide sets out the legislative framework.  This is a complex area of law and the guide is designed to assist professionals in understanding the law. It offers practical information (checklists and commentaries) about how to support people if they want to consider making an ADRT.	National End of Life Care Programme  Available to download: <a href="http://www.endoflifecareforadults.nhs.uk/publications/pubadrtguide">www.endoflifecareforadults.nhs.uk/publications/pubadrtguide</a>  Can also be ordered as a hard copy which the NEoLCP will send out on request. Contact for copies: National End of Life Care Programme (NEoLCP) 3rd Floor, St John's House East Street, Leicester LE1 6NB Tel 0116 222 5103 Email: <a href="mailto:information@eolc.nhs.uk">information@eolc.nhs.uk</a>	It is a resource offering practical information and guidance for professionals rather than for the general public.  It is aimed at people with some prior knowledge and understanding about ACP.  It is a useful reference to understand the legalities of ADRT but it does suggest that further expert advice may need to be sought so users should bear that in mind.

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AgeUK LifeBook	This small booklet is for members of the general public who are interested in thinking about and planning for their future care.	This booklet is designed as a booklet for an individual to write down information on a range of areas, from who insures your car to where you put the TV licence. There is space in the various sections to write down details, contacts and locations of important documents.  It states that its aim is to help people be 'more organised' but that it 'could also be invaluable to a family member or a friend if they need to find important information about you in an emergency'.	To request a printed copy of a LifeBook or a version to be emailed to store and complete on a computer, call 0845 685 1061 and quote reference ALL 721.  Only individual copies can be requested.	This may be a helpful resource for volunteer educators to refer people to - but please note that each individual can only request one copy.
Conversations for Life	Conversations for Life has a website which offers tools and other resources aimed at families, professionals and communities to start talking about end of life care.	This programme of resources aims to "help break the taboo of talking about death and dying in the UK, as a first step towards raising awareness and educating people around the need for end of life conversations while healthy, in order to influence their future care". They have developed various tools including 'The Conversation Game cards', workbooks, and facilitator training either for community groups or professionals.	The website gives more details on the various tools that can be ordered, workshops etc (most have a cost attached).  There are costs attached to resources and training - refer to web-site for more information: <a href="http://www.conversationsforlife.com">www.conversationsforlife.com</a>	It is a useful resource for trainers to search for extra materials. The Conversation Game can be purchased and may be a useful training aid. It is described as a great tool to facilitate discussions, getting people to think and talk about positive values and goals for having the best end of life care possible.
Death & Dying - Making sense of the end of life	This booklet is aimed at any individual interested in thinking through attitudes towards death and dying.	This booklet was designed to accompany a BBC programme which looked at the processes, traditions, taboos and myths that surround death in the UK. It addresses a series of questions about the meaning of death in different religions; societal attitudes towards death; preparing for death; funerals and rituals of death and of remembering people who have died.	BBC / The Open University  The booklet can be ordered or downloaded from the web-link: <a href="http://www.open2.net/deathanddying/booklet.html">www.open2.net/deathanddying/booklet.html</a>	The booklet may be a helpful resource for people to read in preparation for Module 2 of the training programme.

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Difficult Conversations - Communicating with people with Chronic Obstructive Pulmonary Disorder about the End of Life.	This A5 booklet is for anyone caring for someone with COPD (chronic obstructive pulmonary disorder). It is designed to enable people to create an environment where it might be possible to have conversations about ACP should people wish to have them.	The guidance is based on discussions with individuals with COPD as well as carers and former carers affected by COPD. It presents a unique perspective, containing practical hints on what to say and more importantly, what not to say.	The National Council for Palliative Care <a href="http://www.ncpc.org.uk">http://www.ncpc.org.uk</a> Cost £5.00 (£2.50 to NCPC subscribers)	While the booklet is designed for anyone caring for someone with COPD, it offers some useful tips to help in thinking about broaching the topic of ACP.  This may be helpful to refer to for parts of the Modules 2, 3 and 4.
Good Decision Making - the Mental Capacity Act (MCA) and End of Life Care.	Guidance for individuals and informal carers as well as health and social care staff.	This summary guidance is intended to help individuals and informal carers as well as health and social care staff in all settings, for example care homes, hospitals, hospices and primary care.  Its aim is to introduce people to the MCA and its contents, to explain its importance for end of life care decision-making, and to provide a signpost to sources of further guidance and support. It also explains how the MCA can be used to identify and respect people's choices about their future care, and to improve the quality of end of life care decision making.	NCPC <a href="http://www.ncpc.org.uk">http://www.ncpc.org.uk</a> Cost £5.00 (£2.50 to NCPC subscribers)	Useful guide to introduce the Mental Capacity Act.  Also signposts to sources of further guidance.  This would be useful for reference in Module 3.
<b>Leaflet 1</b> Dying Matters Leaflet: <i>5 Things to do before I die</i>	This series of leaflets produced by the Dying Matters Coalition are designed for members looking to publicise their work in raising awareness and promoting conversation about death, dying and bereavement.	Leaflet to promote discussion about end of life between/with family/loved ones.	The Dying Matters Coalition (National Council for Palliative Care)  All these leaflets can be downloaded from the Dying Matters Coalition web-site: <a href="http://www.dyingmatters.org/site/resources">www.dyingmatters.org/site/resources</a>	These leaflets may be resources that volunteer educators can use in their work.
<b>Leaflet 2</b> Dying Matters Leaflet: <i>One last thing</i>		Leaflet to promote discussion about end of life between/with ill or older people.		
<b>Leaflet 3</b> Dying Matters Leaflet: <i>I could do with a chat</i>		Leaflet to promote discussion with bereaved.		
<b>Leaflet 4</b> Dying Matters Leaflet: <i>Someone you know is bereaved</i>		Leaflet to provide guidance following a bereavement.		

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<b>Leaflet 5</b> Dying Matters Leaflet: <i>To do list</i>	This series of leaflets produced by the Dying Matters Coalition are designed for members looking to publicise their work in raising awareness and promoting conversation about death, dying and bereavement.	Leaflet providing information for ill or older people who want to start conversations about the future with family, friends or carers.	The Dying Matters Coalition (National Council for Palliative Care)  All these leaflets can be downloaded from the Dying Matters Coalition web-site: <a href="http://www.dyingmatters.org/site/resources">www.dyingmatters.org/site/resources</a>	These leaflets may be resources that volunteer educators can use in their work.
<b>Leaflet 6</b> Dying Matters Leaflet: <i>Remember when we</i>		Leaflet designed to start conversation about death and dying with someone close to dying.		
<b>Leaflet 7</b> Dying Matters Leaflet: <i>Thinking of you</i>		Leaflet on what to say if someone you know is dying.		
<b>Leaflet 8</b> Dying Matters Leaflet: <i>Talking to children about dying</i>		Information to help you help children understand death.		
<b>Leaflet 9</b> Dying Matters Leaflet: <i>Putting your house in order</i>		Five things you can plan for end of life.		
Dying Matters Postcard: <i>5 Things to do before I die</i>		Post card in A3 or A6 format to list '5 things to do before I die' and '5 things I want to be remembered for'.		
Dying Matters Leaflet: <i>Why Dying Matters</i>		Leaflet to raise the profile of the Dying Matters Coalition. The Coalition's Mission is "to support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make 'living and dying well' the norm".		

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Document	Who is it for	What is it about	Availability	How to use it
Fact sheet 2: Advance Care Planning	These fact sheets are aimed at a broad audience of generalist health and social care staff.	Fact sheet 2: Advance Care Planning provides an introduction to ACP with summary information and outline of key elements, an overview of the discussion process, list of information sources and contact details.	National End of Life Care Programme  Series of nine fact sheets available to download only: <a href="http://www.endoflifecareforadults.nhs.uk/publications/list/fact-sheets/count:5/sort:a-z">www.endoflifecareforadults.nhs.uk/publications/list/fact-sheets/count:5/sort:a-z</a>	The fact sheets offer useful summaries which may be of use to volunteer educators working to raise awareness about ACP.  They could be downloaded and laminated as quick references sheets and/or used as a training tool.  Useful to refer to in Module 3.
Fact sheet 3: Advance Decisions to Refuse Treatment		Fact sheet 3: Advance Decisions to Refuse Treatment provides an introduction to ADRT with summary information and outline of key elements, an advance decisions checklist, list of information sources and contact details.		
Fact sheet 5: Preferred Priorities for Care		Fact sheet 5: Preferred Priorities for Care an Advance Care Plan provides an introduction to PPC with summary information and outline of key elements, an overview of the documentation, list of information sources and contact details.		
Looking to the Future. Creating a Personal Portfolio	This document is for members of the general public who are interested in thinking about and planning for their future care.	Portfolio developed by a small group of volunteers, and researchers, based at the International Observatory on End of Life Care at Lancaster University. This portfolio is an opportunity to bring together information about current needs, preferences and plans for future support and care. It offers guidance on areas of information that are helpful to bring together. There is lots of space to record. It introduces broader issues related to ACP and offers further information if people want to go into more detail to address and record preferences about future care that have a legal status. Further resources are listed.	Lancaster University  Availability: Please email: <a href="mailto:peeredeol@lancaster.ac.uk">peeredeol@lancaster.ac.uk</a> to request copy.	This document is designed for members of the public to bring together information about themselves and their lives in one place. It may also be a useful document for volunteer educators to work through in order to think about their own reactions to all the topics covered and how they might address these and discuss them with close family and friends. This would be helpful preparation in raising these issues with others.  Facilitators might want to collate some of the books and other resources listed at the back of the portfolio. These have been selected by older people as useful and accessible (user friendly) resources.

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Document	Who is it for	What is it about	Availability	How to use it
<p>My Advance Care Plan: This booklet has been developed as a joint initiative between NHS West Kent, Heart of Kent Hospice, Hospice in the Weald and Ellenor Lions Hospice.</p>	<p>An example of a booklet for individuals and their families to use in thinking about and setting out wishes relating to advance care planning.</p> <p>To be held by the individual and shared with professionals caring for them.</p>	<p>The booklet provides a simple explanation about advance care planning and the different options available and provides space for completion.</p>	<p>Available to download at: <a href="http://www.endoflifecareforadults.nhs.uk">www.endoflifecareforadults.nhs.uk</a></p>	<p>It would be useful to give to people on the training course to take away and think about the questions raised. They may also find it useful to refer to post-training. It could be introduced in Module 4 when people have gained an understanding of the issues it covers.</p> <p>Primarily it is a hand held booklet, with space for people to write in - some people may require support to work through some of the sections.</p>
<p>NHS Gloucestershire Planning for your future care - advance care planning.</p>	<p>An excellent example of a booklet for individuals and their families to use in thinking about and setting out wishes relating to advance care planning.</p>	<p>This booklet was designed in consultation with individuals and their carers to produce something that could help people plan and record their preferences and wishes.</p> <p>It contains five sections:</p> <ul style="list-style-type: none"> <li>• Statement of wishes and care preferences</li> <li>• Advance decision making</li> <li>• Putting your affairs in order</li> <li>• Making a will</li> <li>• Funeral planning</li> </ul>	<p>Contact for copies: FREEPOST RRYK-KSGT-AGBR, GUIDE &amp; PALS, NHS Gloucestershire, Sanger House, 5220 Valiant Court, Gloucester Business Park, Brockworth, Gloucester GL3 4FE 0845 658 3888</p> <p>Available to download at: <a href="http://www.endoflifecareforadults.nhs.uk">www.endoflifecareforadults.nhs.uk</a></p>	<p>It would be useful to give to people on the training course to take away and think about the questions raised. They may also find it useful to refer to post-training.</p> <p>It could be introduced in Module 4 when people have gained an understanding of the issues it covers.</p> <p>Primarily it is a workbook, with space for people to write in - some people may require support to work through some of the sections.</p>
<p>Planning for your future care - a guide.</p>	<p>This is an A5 booklet aimed at the general public which explains advance care planning and outlines the different options available to them.</p>	<p>This booklet provides a simple explanation about advance care planning and the different options available. The aim is to provide simple and easy to understand guidance for individuals making advance care plans for their future. It may prove relevant to family members and informal carers.</p>	<p>National End of Life Care Programme</p> <p>Available to download at: <a href="http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare">www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare</a></p> <p>Can also be ordered as a hard copy which the NEoLCP will send out on request. Contact for copies National End of Life Care Programme (NEoLCP), 3rd Floor, St John's House, East Street, Leicester LE1 6NB. Tel 0116 222 5103 Email: <a href="mailto:information@eolc.nhs.uk">information@eolc.nhs.uk</a></p>	<p>This may be a useful support tool to offer to people who are approaching the often difficult situation of discussing advance care planning with people who have a life limiting illness. It may be useful to refer to in Module 3.</p>

## Advance Care Planning (ACP) Resource List

Document	Who is it for	What is it about	Availability	How to use it
The differences between general care planning and decisions made in advance.	This A4 leaflet is aimed at a broad audience of generalist health and social care staff.	This leaflet opens out to an A3 table which clarifies the differences between general care planning, and three decisions that can be made in advance: advance statements, ADRT and DNACPR decisions. For each of the four options it explains in brief: <ul style="list-style-type: none"> <li>• What it covers</li> <li>• Who completes it</li> <li>• What it provides</li> <li>• Legal status</li> <li>• How it can help</li> <li>• Whether it requires a signature and witness to sign</li> <li>• Who should it be shown to</li> </ul>	National End of Life Care Programme Available to download at: <a href="http://www.endoflifecareforadults.nhs.uk/assets/downloads/differences_between_acp_and_adrt.pdf">www.endoflifecareforadults.nhs.uk/assets/downloads/differences_between_acp_and_adrt.pdf</a> Can also be ordered as a hard copy which the NEoLCP will send out on request. Contact for copies National End of Life Care Programme (NEoLCP) 3rd Floor, St John's House East Street, Leicester LE1 6NB Tel 0116 222 5103 Email: <a href="mailto:information@eolc.nhs.uk">information@eolc.nhs.uk</a>	A useful resource for training to clarify the key points and differences between: <ul style="list-style-type: none"> <li>• General care planning</li> <li>• Advance Care Planning (ACP)</li> <li>• Advance Decisions to Refuse Treatment (ADRT)</li> </ul> and <ul style="list-style-type: none"> <li>• Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) element of ADRT</li> </ul> Useful resource for Module 3.
Thinking Ahead: My Way, My Choice, My Life at the End	People with developmental disabilities (US term) who are thinking about planning and writing down preferences for their future care.	This is an American resource for people with developmental disabilities. It is designed to be an 'easy to use' workbook to help people in making decisions about the end of their life. It is available in English, Spanish, and Chinese and there is a series of DVDs to accompany the booklet which can be viewed online.  As a resource from the US it follows the US legal framework and terms.	The booklet and videos can be downloaded/viewed at: <a href="http://www.dds.ca.gov/consumercorner/ThinkingAhead.cfm">www.dds.ca.gov/consumercorner/ThinkingAhead.cfm</a>	It is similar to the Lancaster Portfolio, the AgeUK LifeBook and the Gloucestershire ACP guide, but is aimed at a specific audience of people with developmental disabilities. It incorporates symbols which can help people who find it difficult to read. One suggestion is that it might be adaptable for use with people in care homes.
When I die	For people with intellectual disabilities (UK term) to plan for their future care and funeral plans, alongside their advocates.	An End of Life book which provides an example of what a person centred approach to the 'end of life' should look like. It is laid out using photosymbols which are a collection of pictures to assist in developing easy read information - but these are copyrighted.  Permission is given for individuals to download and use the booklet as an example in their work.	Available to download: <a href="http://www.haringey.gov.uk/social_story_example_-_end_of_life.pdf">www.haringey.gov.uk/social_story_example_-_end_of_life.pdf</a>  Photosymbols may be viewed at <a href="http://www.photosymbols.com">www.photosymbols.com</a>	A useful example of materials that are suitable for people with intellectual disabilities.



## Advance Care Planning (ACP) Resource List

Document	Who is it for	What is it about	Availability	How to use it
Video clips (discuss which to include - there may be others and ones in development)				
Consider the Conversation Documentary Film		Excerpt from 'Consider the Conversation: A Documentary on a Taboo Subject' - available on You Tube.  From the US examines "multiple perspectives on end-of-life care and includes information and experiences gathered from interviews with individuals including those receiving care, family members, doctors, nurses, clergy, social workers, and national experts on death and dying"	<a href="http://www.youtube.com/watch?v=Azu4t-XBvTM">http://www.youtube.com/watch?v=Azu4t-XBvTM</a>	This may be useful in Module 4.
Video clip from US Caregiver Centre		The video clip accompanies a Planning Guide developed in the US called Sharing Your Wishes: Give Them Peace of Mind, Not Tough Choices. Sharing Your Wishes is a US organisation which works to assist individuals to plan ahead to 'improve health care decision making'.	<a href="http://www.youtube.com/watch?v=Xw7gpsjeRnk&amp;feature=related">http://www.youtube.com/watch?v=Xw7gpsjeRnk&amp;feature=related</a>	May be useful in Module 3.
Dying Matters video		Dying Matters has produced 'A Party for Kath' a 5-minute film which aims to demonstrate the benefits of greater openness around death and dying and to encourage people to think about and discuss their end of life wishes.	The Dying Matters Coalition <a href="http://www.dyingmatters.org/site/party-for-kath">www.dyingmatters.org/site/party-for-kath</a>	May be useful to refer to in any of the Modules - could be an introductory video to show.
Dying Matters 'talking heads series'		One clip shows Peter Ashley talking about his advance wishes and what planning he has done.	<a href="http://www.youtube.com/watch?v=-S--Y2mpESw">http://www.youtube.com/watch?v=-S--Y2mpESw</a>	

You may wish to check for updates on the following websites;

National End of Life Care Programme (NEoLCP) [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

Dying Matters [www.dyingmatters.org](http://www.dyingmatters.org)

The National Council for Palliative Care (NCPC) [www.ncpc.org.uk](http://www.ncpc.org.uk)



**THINKING & PLANNING AHEAD**  
Learning from each other

available on the **NEoLCP** and **Dying Matters** websites

A volunteer training programme about **Advance Care Planning**

