## **Advance Care Planning Guide**

# Planning for Your Future Care and Wellbeing

- Preparing for the future and your health and wellbeing needs
- Identifying practical arrangements
- Enabling the right care to be given at the right time and in the right place for you



















#### Advance Care Planning Guide

#### How it can help you plan your future care

Please note that this booklet and Sections are not designed to be completed all at once. It can be filled in over a period of time, as and when you feel comfortable to do so, but a good place to start is Section One "Statement of your wishes and care preferences"

Advance Care Planning can help you plan for the future. It gives you an opportunity to think about, talk about and write down your preferences and priorities for your future care, including how you want to receive your care.

The choice is yours as to who you share the information with. By recording your preferences in this booklet it will help to ensure that your wishes are taken into account.

Advance Care Planning can help you and your carers (family and friends who are involved in your care) to understand what is important to you. The plan provides an ideal opportunity to discuss and record in writing your views with those who are close to you. It will help you to be clear about the decisions you make and it will allow you to record your wishes in writing so that they can be carried out at the appropriate time.

Remember that your feelings and priorities may change over time. You have choices in what may happen in the future such as being able to remain living independently at home. This document allows you to voice your own preferred choices.

You can change what you have written whenever you wish to, and it would be advisable to review your plan regularly (every 3-6 months) to make sure that it still reflects what you want. Remember to sign and date this document when you review it so that it is clear to others.

There are <b>Six Sections</b> in total:	
Statement of your wishes and care preferences	Section 1
Putting your affairs in order	Section 2
Making a Will	Section 3
Funeral Planning	Section 4
Advance Decision Making	Section 5
Reminder checklist	Section 6

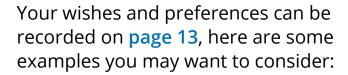


# Section 1a - Statement of your wishes and care preferences

This section is for you to record any wishes or preferences that would be important to you should you ever become unwell, or have difficulty in making decisions for yourself. This will give everyone (family, carers and professionals) a clear idea of knowing what is important to you when deciding what needs to happen. Your wishes and preferences must be considered at these times though they are not legally binding.

If you want to refuse a specific treatment then the section in this guide about 'Advance Decisions' is available which is a legal way to refuse treatments that may be offered to you in the future (Section 5). An Advance Decision is different to an advance statement.





- If you become ill, where you might prefer to be treated (at home or in hospital for example).
- What might help you feel relaxed and comfortable should you need to receive care or treatment at home or in hospital.
- Who you would like with you or who you would like to visit you should you need care or treatment at home or in hospital.
- Who you would like to look after your dependants and pets should you be unable to do so because of illness.

- What would be important regarding religious, spiritual or cultural concerns for you should you need care or treatment at home or in hospital.
- Who you would like to be informed if you become ill and need care or treatment.
- If your health/condition worsens, how much information you would like to receive about how serious your condition might be.
- What your wishes and choices regarding possible organ or tissue donation are, as you may need to make your family aware of your wishes as their consent will also be sought if you have chosen to donate your organs or tissue (please see below for further information).

The corresponding form relating to this section can be found in **Section 1b** (page 13)

#### **Further Information**

www.endoflifecareforadults.nhs.uk

www.uktransplant.org.uk

### Section 2a - Putting Your Affairs in Order Checklist

Ensuring that your paper work and documents are up to date and easier to find will save time and reduce anxiety for your family/next of kin if you become unable to attend to your affairs or if you are taken ill or suddenly die.

Your next of kin can be either your partner, a member of your family or a good friend but it is important to discuss with those you have chosen as your next of kin that they are willing to be so¹.

### Information you may wish to start putting together

Information you may wish to start putting together and have recorded in a safe place include bank name and account details, Insurance Policies, Pension Details, Passport, Birth/Marriage Certification, House Details to name a few. A tick box list can be found in Section 2b (page 18) which you can use as a reminder of what to think about. Have you nominated someone you can trust to tell them where your safe place is, so they will know where this information is kept in order to be able to access the details you have recorded if the need ever arises?

#### Appointing Someone to Make Decisions for You

There are some situations when someone is able to foresee that they will, in the future, deteriorate mentally (e.g. dementia). If this is the case they may well decide to ask a specific person to undertake the responsibility for making decisions for them if and when they are unable to do so themselves. That person is given Lasting Power of Attorney (LPA).

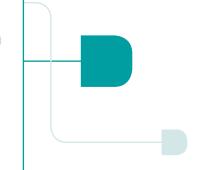
The person you choose can be your partner, a friend, a relative, or a professional. More than one person can act as attorney on your behalf. Lasting Power of Attorneys are exclusive to you and the amount of power and limits of that power are decided by you.

The role of attorney involves a great deal of power and responsibility, so make sure you think carefully about who you choose. You must be able to trust them to make decisions in your best interests.

<sup>1</sup>There is no legal definition of next of kin and you should consider very carefully who you state to be your next of kin, particularly if this is someone outside your immediate family.

#### There are two types of Lasting Power of Attorney:

- A Property and Financial Affairs LPA covers decisions about your property and money i.e. managing a bank or building society, paying bills, collecting benefits or a pension and selling your home. This can be used as soon as it's registered with your permission.
- A Personal Welfare LPA covers decisions about your healthcare and personal welfare ie. your daily routine (washing dressing, eating), medical care, moving into a care home and life-sustaining treatment. This can only be used when you're unable to make your own decisions.



You can choose to make one type or both. Forms need to be completed and then registered with the Office of the Public Guardian. You can fill in forms on the internet - https://www.gov.uk/power-of-attorney/make-lasting-power, or you can request forms to be posted to you. The Office of Public Guardian (OPG) can give you details of organisations to help you use the online service if you don't have a computer or if you want to use the online service but need some help.

There is a cost involved to register an LPA however you can check with organisations such as Age UK or Citizens Advice Bureau to see if you are eligible for either a reduction or exemption. You are advised to look at the OPG website to find out the current fee for registration.

You can cancel your LPA if you no longer need it or want to make a new one.

The corresponding form relating to this section can be found in Section 2b (page 18)

#### **Further Information**

#### Gov.uk Website

https://www.gov.uk/power-ofattorney/overview

#### Office of the Public Guardian (OPG)

Tel: 0300 456 0300 (low call rate) Web: www.publicguardian.gov.uk

#### Age UK

Tel: **0300 303 1234** 

#### Citizens Advice Bureau

Web: www.citizensadvice.org.uk

#### Section 3 - Making a Will

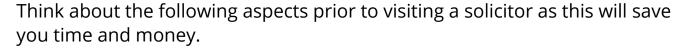
Many problems occur when a person dies without making a Will as there are clear laws which dictate how your possessions would be allocated.

If there is no Will the time taken to sort things out can be lengthy and expensive and will cause added stress to your family/next of kin.

In addition, the outcome from this process may not be as you would wish, so it is advisable to make a Will to ensure that your belongings are left to the people you want to inherit them.

You can make a Will without a solicitor, and forms can be purchased from stationers or via the internet. This is only advisable if the Will is straightforward. The Law Society advises that specialist advice is sought from a solicitor if you have a number of beneficiaries and your finances are complicated.





- A list of all beneficiaries (people who you would like to benefit from your Will) - and what you would like them to receive
- A list of your possessions savings, pensions, insurance policies, property etc
- Any arrangements you want for your dependants or pets
- Decide who will be your
   executor(s) the person/s who will
   deal with distributing your money
   and possessions after your death.
   You may have up to four, but it is
   a good idea to have at least two in
   case one dies before you do. They
   can also be beneficiaries and care
   should be taken when choosing
   executors to ensure that they are
   suitable and also willing.

The Solicitors Regulation Authority (information below) is able to provide advice on how to find a solicitor who

is best suited to your individual needs, as well as what information you should expect to receive from your solicitor.

#### **Further Information**

Citizen's Advice Bureau

www.citizensadvice.org.uk

**Solicitors Regulation Authority (SRA)** 

Tel: 0870 606 2555 (national call rate)

Web: www.sra.org.uk

#### Section 5a - Advance Decision Making

An **Advance Decision** (previously known as a Living Will) is different from Advance Statement of Wishes and Care Preferences as it is a formal, legally binding document which allows an individual to refuse certain treatments. A person must be over eighteen to make an Advance Decision and must have mental capacity to do so.

It does not allow for a request to have life ended and cannot be used to request medical treatments.

An Advance Decision (AD) is **very** specific and is used in situations when particular treatments would not be acceptable to someone. An example would be if a person had a severe stroke which resulted in swallowing problems. If the thought of being fed by alternative methods was not tolerable then this could be documented formally as an Advance Decision.

In order to make an Advance Decision advice should be sought from someone who understands the complexity of the process such as a health care professional e.g. your GP/ Doctor, or a solicitor.

An Advance Decision to refuse treatment can be made verbally, but it is preferable for decisions to be made in writing. If the Advance Decision includes the refusal for life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'.

An Advance Decision will only be used if, at some time in the future, you lose the ability to make your own decisions about your medical treatment. To be valid, an Advance Decision must be made before you lose your ability to make such decisions. You can change your mind about your Advance Decision, or amend it at anytime, provided you still have the capacity to do so.

### An Advance Decision cannot be used to:

- Refuse basic care essential to keep you comfortable, such as washing or bathing
- Refuse the offer of food or drink by mouth (but can be used to refuse feeding by tube(s))
- Refuse the use of measures solely designed to maintain comfort – for example painkillers (which relieve pain but do not treat the condition)
- Refuse treatment for a mental disorder in the event that you are detained under the Mental Health Act 1983

The corresponding form relating to this section can be found in **Section 5b** (page 22)

#### **Further Information**

www.direct.gov.uk

www.endoflifecareforadults.nhs.uk

www.opsi.giv.uk/acts/acts2005/en/ukpgaen\_20050009\_en\_l.htm

Most of the forms included in this guide are non-legally binding, the table below shows which are legally binding or non-legally binding

Section	Legally Binding	Non-legally Binding
Your Priorities for Care		✓
Putting your affairs in order		✓
Funeral Planning		✓
Reminder of things to do		✓
Advance Decision Document	✓	

The forms included this guide can be found as below:

Section 1b	Your priorities for care	Page 13
Section 2b	Putting Your Affairs in Order Checklist	Page 18
Section 4	Funeral Planning	Page 21
Section 5b	Advance Decision Document	Page 22
Section 6	Reminder of things to do	Page 27



#### Section 1b - Your priorities for care

(A non-legally binding document to represent your future hopes and wishes)

Ideally keep this document to hand, share it with anyone involved in your care, including your GP (they may wish to keep a copy for their own records) and let them know when it is changed.

Your Name	
Date	
Address	
	Postcode
Distinguishing features (e.g. tattoos, birt	hmarks)
Things about me that I would like you	ı to know
Name I like to be called	
Carer / the person who knows me best	
I would like you to know	
My life so far (family, home, background and treasured possessions)	
Current interests	
The routines important to me	
My diagnosis/diagnoses and what I understand about this	

<b>Do you have a Legal Advance Decision?</b> (Formally known as a Living Will)¹	Yes□	No 🗆
If yes, where do you keep it and who has a copy?		
You may wish to name someone - or even more than one person - be asked about your care if you are not able to make decisions for person may be a close family member, a friend or any other person Please state below who else you would like to be involved in making	yourself. on you cho	. This
Contact 1		
Relationship to you		
Telephone		
Address		
Does the person have a Lasting Power of Attorney for you?  If yes please state which type - see page 7 for further information	Yes□	No 🗆
Type		
Contact 2		
Relationship to you		
Telephone		
Address		
Does the person have a Lasting Power of Attorney for you?  If yes please state which type - see page 7 for further information	Yes□	No 🗆
Type		

<sup>1</sup> An Advance Decision (formally known as a Living Will) is a formal, legally binding document which allows an individual to refuse certain treatments. A person must be over eighteen to make an Advance Decision and must have mental capacity to do so.

Page 5 of this guide may help you to complete the questions below. Consider each of these questions carefully.
Do you have any special requests or preferences regarding your future care?
If your condition deteriorates where would you most like to be cared for?
Generally is there anything you would ideally like to avoid happening to you?
Do you have any comments or wishes that you would like to share with others?

### Section 1b - Your priorities for care

(A non-legally binding document to represent your future hopes and wishes)

Your Name Date	
Family Member / Carer / Next of Kin Signa Date	ature (if present)
Health / Social Care Professional Date	
Details of any other family members in Planning discussions	volved in Advance Care
I am happy and give consent for the info document to be shared with relevant h - I.e. GP, Consultant, Specialist Nurse en	ealthcare professionals
Signed	Date
Please sign here each time you review	and update this to your care plan
Signed	Date

Remember to regularly review (e.g. every 3-6 months) to ensure that this document still represents your wishes. Sign and date any changes you make.

### Is there anything else important to you that you wish to document here?

#### e.g.:

- you are registered on the Organ and Tissue donation register,
- · caring for pets,
- your faith or belief (including religious preferences),
- music or films that you like to listen to/watch,
- adaptations made to your house so that you can remain living independently at home.

### Section 2b - Putting Your Affairs in Order Checklist

Ensuring that your paper work and documents are up to date and easier to find will save time and reduce anxiety for your family/next of kin if you become unable to attend to your affairs or if you are taken ill or suddenly die.

#### Information you may wish to start putting together

Use the tick boxes below as a reminder that you have thought about and recorded in a safe place the details listed. Have you nominated someone you can trust who will be able to access those details if the need ever arises?

You	r Name:	
Date of Birth:		
	Bank Name and where account details (including credit card) are stored	
	Insurance Policies	
	Pension Details	
	Passport	
	Birth / Marriage Certificate	
	House Details Mortgage, House Deeds, Landlord, Warden etc	
	Hire Purchase Agreements	
	Will (See page 8 for further guidance)	
	Other Important Documents / Contacts e.g. Solicitor, financial information	
	Details of any Funeral Arrangements (see page 19 and 21)	
	Domestic Arrangement i.e. paper delivery, window cleaner, pets	
	Addresses and Contact Number of Family, Friends and Colleagues	
	Tax Office Address and Contact Details	
	Advance Decision	

I nominate	(Family Mem	ber/Carer/Next of Kin)
		ber, as the person who will etailed information if required
Signed	(self)	Date
Signed	(nominee)	Date

This section allows an opportunity to consider specific wishes and preferences relating to end of life (as with all sections of this document this is optional and you may choose not to complete it).

Five things I like to do	Five things I don't like to do	Five things I would like to be remembered for
1.	1.	1.
2.	2.	2.
3.	3.	3.
4.	4.	4.
5.	5.	5.



How would you like your final days to look and sound? (e.g. what music/pictures/fragrance would you like around you?)

Who would you like with you at end of life if possible?

Where would you prefer to die if possible? (e.g. home, care home, hospital or hospice)



## ■ Section 4 - Funeral Planning

Your Name:		
	Details	
Person I wish to be responsible for making my funeral arrangements		
People who are important to me who need to know what has happened		
My preferred funeral director is		
My pre-paid funeral plan is with		
I wish to be buried / cremated / other (e.g. donation for medical science – specific documents will need to be signed)		
I wish my funeral service to be in accordance with my faith. Please state (if any)		
I would like the venue to be		
I would like the following music, hymns or readings included		
I would like the following person(s) to conduct the service if possible		
Other details and information you would like to record e.g. donations to named charity, flowers, people to be informed		

### Section 5b Advance Decision Document (part 1 of 5)

Your Name:	
Date of Birth:	
Date of Advance Decision completed:	

Copies need to be provided to all professionals involved in your care, otherwise they will not necessarily know your wishes and be able to act in accordance with them

- Your GP to keep with your records
- Someone who you wish to be consulted about your treatment should this ever be necessary.
   (e.g. next of kin, solicitor)
- A member of your Care Team, Hospital Consultant, Community Palliative Care Nurse, Hospice Team, District Nurse, Mental Health Nurse or Care Home as appropriate

Please make sure that health care professionals and others are aware that your Advance Decision exists.

Please discuss with your health professionals to confirm if the ambulance service needs to be aware that an Advance Decision exists. If so, health professionals are able to let the ambulance service know on your behalf, in case they are called to your address.

All forms must be signed by at least one person who is not a close relative or expecting to benefit from your will (e.g. health care professional).

You might also wish to consult with a solicitor.

Remember to review this document at regular intervals (every three to six months) to ensure it still represents your wishes. Signing and dating at the bottom when you do this will indicate how recently you have thought about it. If you change your mind about anything you have written, tell your GP, health care professional, next of kin or appointed representative, amend the document accordingly and provide them with an updated copy.



### Section 5b Advance Decision Document (part 2 of 5)

Your Name:	
Date of Birth:	
Date of Advance Decision completed:	
I would like the following people to be for me to make decisions for myself.	consulted if it ever becomes too difficult
Contact 1	Contact 2
Relationship to you	Relationship to you
Telephone	Telephone
Address	
Does the person have an Enduring or Lasting Power of Attorney for you?  If yes please state which type - see below for which type (further information on page 6)	Does the person have an Enduring or Lasting Power of Attorney for you?  If yes please state which type - see below for which type (further information on page 6)
Type	Type
Full Marca	concerned this Advance Decision is made by me:
Of (Address)	
I am writing this at a time when I am able to to considered my situation. I am aware that I ha	think things through clearly and I have carefully ave been diagnosed as suffering from:
I am over eighteen years old and I am writing	this of my own free will.
Signed	Date

### Section 5b Advance Decision Document (part 3 of 5)

Your Name:	
Date of Birth:	
Date of Advance Decision completed:	

I declare that if I become incapable of making decisions about my medical care,
then and in those circumstances, my directions are as follows: I refuse to receive
the specific treatments stated below even if my life is at risk as a result.

Signature	
Jigi latai C	

(Continue in box below / on a separate sheet if necessary)

Treatment to be refused (E.g. resuscitation, stoma formation, surgery, blood transfusion)	Details of situations you have anticipated in which the refusal would be valid (see examples below)

#### **Examples**

- I refuse Cardiopulmonary Resuscitation (CPR) in the event of a cardiac arrest (if your heart and lungs stop working)
- I refuse all life-sustaining treatment (including but not limited to CPR, artificial nutrition and hydration, breathing machines) if I am diagnosed as being in a vegetative or minimally conscious state
- I refuse all life-sustaining treatment (including but not limited to CPR, artificial nutrition and hydration, breathing machines) if I lose capacity to the extent that I cannot remember recent events or recognise or communicate with my family members

If unsure of medical condition and impact of refusal of treatment, please seek medical advice.

### Section 5b Advance Decision Document (part 4 of 5)

Your Name:	
Date of Birth:	
Date of Advance Decision complete	ed:
I reserve the right to revoke (cancel) do so it should be taken to represen	this Advance Decision at any time, but unless it my continuing directions.
My General Practitioner is:	
Name if GP	
Address	
Telephone	
Before signing this I have talked it over v	vith my:
GP	Dr
Nurse	
Hospice Consultant / Hospital Doctor	Dr
Solicitor	
Family / Carer / Next of Kin	
	this with at least one of the above or hospice then the consultant caring for bout the scope of this advance decision.
I have attached a sheet with further	wishes about my treatment.
Yes □ No □	
I acknowledge that the information relevant healthcare professionals?	n in this document will be shared with other
Yes□ No□	
Signed	Date

### Section 5b Advance Decision Document (part 5 of 5)

Your Name:				
Date of Birth:				
Date of Advance Decision	on completed:			
Witnesses: I/We testify the presence, and made it clude on the large of any presence and I/we believe it was more to gain to g	ear to me/us tha sure being broug nade by his/her o	at he/she ght on hi own wish	e understoc im/her to m	od what it meant. I/We nake such a Decision
Only one witness is legal	ly required.			
Witnessed by:				
•	Hospital Doctor)	Witne	•	se family, or s expecting to from your will)
Signature  Date		Signatu	ıre	
Name		Date		
Address		Name	•••••	
		Addres	S	
		•••••		
Reviews: This directive w	as reviewed and	d confirn	ned by me	on:
Signed	Witness		Date	Time
Signed	Witness		Date	Time
Signed	Witness		Date	Time
Signed	Witness		Date	Time



### Section 6 - Reminder of things to do

Now that you have completed one, some or all of the forms in this guide, a checklist of what to do next is below in case of assistance:

Who have you told that you have completed the form(s)? I.e. • GP
Family Member
• Carer
Next of kin
• Consultant
Social worker
Have you given a copy of the form(s) to all of the above?
Have you signed the form(s) where a signature is needed?
Where are the completed form(s) kept?
If you have completed the form(s) on your computer, have you printed off a copy (copies) and signed it (them)?
If you have a message in a bottle in your fridge, have you put information in there to say that you have completed an advance decision and where to find it?
Have you reviewed what you have written in the form(s) (suggested review of every 3-6 months) to make sure what you have written is still correct or if it needs changing?
Have you told people (as above) that you have reviewed the advance decision and made any changes?

### Further Information

Who to contact	Advice or Information Provided
Admiral Nurse Service Tel: 0845 257 9406 Email: direct@dementiauk.org	Community dementia nurse service offering specialist support, information and advice for the carers of people with dementia. Admiral Nurses are mental health nurses specialising in dementia care
Alzheimer's Society Tel: 0300 222 11 22 Web: www.alzheimers.org.uk	Provide information, advice and support including advance decisions and advance statements to people living with or affected by Dementia
Age UK Tel: 0300 303 12 34 Web: www.ageuk.org.uk	Provide advice, information and advocacy services including advice on services, regarding benefits and entitlements, legal advice, means testing for Power of Attorney registration
British Lung Foundation  Tel: 0300 003 05 55  Web: www.blf.org.uk  Email: enquiries@blf.org.uk  helpline@blf.org.uk	Provide support for all those affected by a lung condition through a helpline, web community, penpals, Breathe Easy support groups, booklets. Lung disease can be frightening and debilitating. Also offer hope and support at every step so that no one has to face it alone
Citizen's Advice Bureau Telephone No's for local offices: Blackburn with Darwen: 03444 889 622 Burnley and Pendle: 01282 616 750 Hyndburn: 03444 889 622 Ribble Valley: 01200 428 966 Rossendale: 0844 499 4121 Web: www.citizensadvice.org.uk	Provide help for people to resolve their legal, money and other problems by providing free, independent and confidential advice
Blackburn with Darwen Carers Service Tel: 01254 688 440 Web: www.bwdcarers.org.uk	Provide information, advice and support for carers living in Blackburn with Darwen

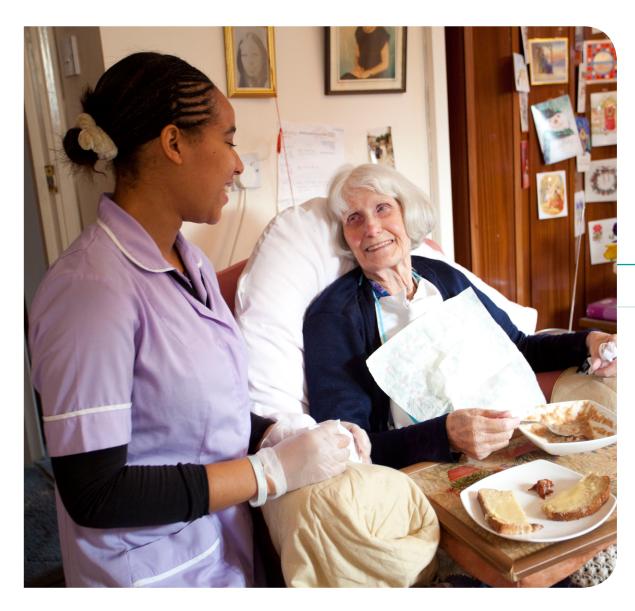
Carers Link Lancashire (Covering Burnley, Pendle, Rossendale, Hyndburn and Ribble Valley) Tel: 0345 688 7113 Web: www.eastlancscarers.org.uk	Provide information, advice and support for carers living in East Lancashire
Compassion in Dying Tel: 0800 999 2434 Web: www.compassionindying.org.uk	Provides information and support to people to complete an Advance Decision, Advance Statement or a Health and Welfare Lasting Power of Attorney
A Lancashire Information and advice service Tel: 0303 333 1111	Free and local information in Lancashire and for practical support, guidance and / or information including managing finances, social services, getting the right help and support, housing support, repair and maintenance
Local Hospices: East Lancashire Hospice Tel: 01254 733 400 Web: eastlancshospice.org.uk	Provide specialist, supportive and end of life care for people and their families
Pendleside Hospice Tel: 01282 440 100 Web: www.pendleside.org.uk	
Rossendale Hospice Tel: 01254 733400 Web: www.rossendalehospice.org	
Organ Donor Line Tel: 0300 123 23 23 Web: www.organdonation.nhs.uk	Registration of organ donation either by phone or online and advice line for queries.
Solicitors Regulation Authority (SRA) Tel: 0870 606 2555 (national call rate) Web: www.sra.org.uk	Advice on how to contact a local solicitor
Information booklets about the Mental Capacity Act (2005) Tel: 02380 878 038 (national rates) Web: www.dca.gov.uk	Advice line and Information booklets about Mental Capacity Act

#### Acknowledgements

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- Pennine Lancashire Dementia Steering Group
- Pennine Lancashire Palliative and End of Life Steering Group
- East Lancashire Critical Friends Group
- Blackburn with Darwen and East Lancashire Focus Groups

If you require this leaflet in other formats or languages please ring 01282 644700



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