



# Planning Ahead

## Advance Care Planning



Advance Care Planning is useful for having discussions with family and friends, as well as healthcare professionals and can bring a sense of relief that difficult subjects have been raised.

This booklet has been designed in consultation with patients and carers. It explains the choices you can make and serves as a place to record all your thoughts and wishes so that you can be certain they will be taken into account. It is up to you who you choose to share this information with.

You should remember that your feelings and priorities may change over time and it is advisable to regularly review what you have written.

We know that not everyone will want to engage in this process or for some, now may simply not be the right time. It is up to you when and if you choose to complete your Advance Care Planning.

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# 1. Identifying your wishes

It may be difficult to talk about your future care with your family and friends because it can be emotional or they might not agree with your choices. However, having this discussion can be very useful just to get the difficult issues out in the open.

People cope with illness in different ways so don't be surprised if others' needs for discussion and openness are different to yours.

At the back of this booklet you can document your wishes and preferences (your Advance Wishes for Care) which will always be taken into account when planning your care.

## Some things you may want to think about:



- **What is important to you as a person?** Your care and surroundings should reflect as much of who you are as possible. This is true for care at all stages of your illness including as the end of life approaches.
- **Are there cultural beliefs, practices or preferences that might affect you at times of significant illness?** Are there aspects of medical care that you would wish to forgo or to have withheld because of your cultural beliefs?
- **Where would you ideally like to be cared for at the end of your life?** This might be at home or in a nursing home, hospital, or Hospice. You may find that when the time comes you change your mind. Or your preferred place of care is not available, perhaps due to the level of nursing required, carers becoming ill, lack of beds or need for hospital specific tests. However, deciding on your preference now will give you the best chance of achieving your wishes.
- **How would you want your final days to look and sound?** Would you like any specific flowers, pictures, photographs, music, films or television programmes to be close to hand.
- **Do you want to be given as much information as possible – even about potential timescales – and would you want others to know too?**
- **If you have children, elderly or other vulnerable relatives, who would you want to talk to them about your illness if you could not?**
- **Are there any specific practices that are important to you at the time of death or afterwards that we should know about?**

- **Do you want to reconnect, revisit or re-evaluate your beliefs?**

Some people find it helpful to meet with a spiritual or religious leader. The Hospice has a Chaplain who will be happy to meet with you whether you have faith or not. Or you may want to contact another spiritual or religious leader, or have us contact one on your behalf. Just ask your healthcare team.

- **Do you have any ideas about organ donation or medical research?**

You may want to donate certain organs – like corneas – to patients in need of them, or consider other organs for medical research. You will need to sign specific documentation for this and there can be quite strict criteria for acceptance, so your illness or treatments may mean it is not possible for you to donate. However, recording your wishes now is the best way to let your healthcare team know you would like to be considered as an organ donor.

## 2. Identifying someone to make decisions on your behalf

If you become unable to participate in decision-making at any point, we as healthcare professionals, would consult your next of kin and key carers (who you can identify in advance) as well as the multi-professional healthcare team.

Based on your previously expressed wishes and in the context of the clinical situation, a decision would be made that is in your best interests. For most people this way of making decisions is a good one.

However, you may choose to give another person legal authority to make decisions on your behalf. This can be a relative, friend or solicitor and is called a Lasting Power of Attorney (LPA) which enables you to give another person the right to make decisions about your property and affairs and/or your personal welfare.

A 'Health and Welfare LPA' will only take effect when you lack the capacity to make decisions. A 'Property and Financial Affairs LPA' is different and this individual can start managing your financial affairs as soon as the LPA is registered, unless it is specifically stated that this should only happen after you lose capacity.

There are special rules about appointing an LPA and it can take a considerable amount of time to complete the process, so it is best to start as early as you can. You can get a form from the Office of the Public Guardian (OPG) or stationery shops that provide legal packs. The 'Making a Lasting Power of Attorney' form will explain what to do. Your LPA will need to be registered with the OPG before it can be used. See contact details on page 9.

# 3. Practical planning

## **Writing a Will**

Ideally you should have an up to date Will that records your wishes, that way you can be confident your friends and family will be provided for and your assets distributed as you wish. The Law Society recommends that a Will should be drawn up with face-to-face advice from a specialist Solicitor.

It may be helpful to start making a list of all your possessions and the people or charities you want to provide for, including any property you may wish to divide in a certain way. A Will can name guardians for any dependent children and record your wish to leave money or property in trust for children or grandchildren. Think also about arrangements for the care of pets or other responsibilities.

## **Putting documentation in order**

How easy would it be for your next of kin to find important documents?

You might want to make a list of where to find important contact details, passwords and documents for ease of access. There is a form on page 25 to help you with this.

## **A 'List for Living'**

Have a list of goals you'd like to achieve - a bucket list - these can range from the serious to the crazy and it can be great fun to think outside the box!

You might long to settle a rift in the family, swim with dolphins or teach your dog to high-five! There are several apps and websites that can help you put your list together.

Spend some time with loved ones sharing your hopes and dreams; even if these are not totally achievable, a part of it may be possible. You may find that there are organisations who can help you make some of your dreams a reality and you can ask your local Hospice for further information. Your List for Living can be found on page 11.

# 4. Celebrating your life

At some point you may feel like thinking about how you would want to have your life celebrated and how you would like to be remembered after your death.

Sometimes it can be helpful to write letters to close family and friends, or put together a 'memory box' for someone special.

Many people want a formal act of remembrance after their death, which may be religious or non-religious – do you have a preference on this? It can be helpful to discuss your thoughts with your faith leader, the Hospice or hospital chaplain, or a Funeral Director.

If you would like to start thinking about plans for celebrating your life, there is a form included on page 17 to prompt you and record your wishes.

You may feel that it is too hard to be involved in planning for celebrating your life, if so you can appoint someone else to do this for you.

"It was an odd thing to do, plan for when I wasn't here anymore. But I had always been clear on how I wanted it to be and wrote it in my Advance Care Planning booklet so my husband would know." - **Hospice patient**

# 5. Refusal of treatments or interventions

You may decide that you want to refuse particular medical treatments and you can do this by making an Advance Decision to Refuse Treatment (ADRT). A form and instructions are included on page 19.

This will only be used if, at some point in the future, you lose the ability to make your own decisions about treatment. If you are still able to be involved in decision-making, you will be consulted if the situation arises. Remember you can always change your mind at any point.

In order for an ADRT to be useful, it must be as specific as possible. For example, you may want to refuse a treatment in some circumstances but not in others. If so, you must specify all the circumstances in which you want to refuse this particular treatment.

If you want to make an ADRT then it is advisable to discuss this and write it with a healthcare professional who is fully aware of your medical history. This should ensure that it is as specific as possible and is appropriately shared with ambulance services and out of hours medical professionals.

It is important to remember that you cannot make an advance decision to **request** a medical treatment or to have life ended.



Refusing **resuscitation** is an example of a treatment you may wish to refuse in advance. You may decide – in discussion with your healthcare team and family – that resuscitation is not something that you want attempted.

If there is a chance that resuscitation could be helpful then this will be discussed with you to work out what would be the best decision for you. Where a decision has not been made the healthcare professionals will always have to attempt resuscitation.

If you are certain that you do not want resuscitation, there is a separate Do Not Attempt Cardiopulmonary Resuscitation form (DNACPR) available. You can ask your healthcare team for advice and information about completing this form.



# 6. Where to find further information

## **Dying Matters**

Dying Matters aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement. They have a range of leaflets focused on having discussions and planning ahead. Visit: [www.dyingmatters.org/overview/resources](http://www.dyingmatters.org/overview/resources)

## **Office of the Public Guardian**

The Office of the Public Guardian is there to protect people who lack the capacity to make their own decisions. They hold forms and guidance on appointing a Lasting Power of Attorney. Visit: [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

## **Your local hospice:**

**Weston Hospicecare** – supporting people in Weston-super-Mare, North Somerset and the surrounding areas from Yatton in the north, Burnham on Sea and Wedmore in the south and as far east as Blagdon and Cheddar. Visit: [www.westonhospicecare.org.uk](http://www.westonhospicecare.org.uk)

**St Peter's Hospice** – supporting people in Bristol and the surrounding area.

Visit: [www.stpetershospice.org.uk](http://www.stpetershospice.org.uk)

**St Margaret's Hospice** – supporting people in Taunton and Somerset.

Visit: [www.somerset-hospice.org.uk](http://www.somerset-hospice.org.uk)

There are a number of charities that may be able to offer you specialist help and advice relating to your illness or circumstances. If you'd like an idea of organisations that may be able to support you, other than your local Hospice, ask your healthcare team.

## **Organ Donation**

Visit: [www.organdonation.nhs.uk/](http://www.organdonation.nhs.uk/)

If you need help thinking of a list for living, [www.bucketlist.org](http://www.bucketlist.org) has around 10,000 ideas.

Information on what to do after a death, as well as information on Wills and funeral planning is available on the HMRC website: [www.gov.uk/after-a-death/arrange-the-funeral](http://www.gov.uk/after-a-death/arrange-the-funeral)

If you need this leaflet in large print or alternative format or language, then contact your health care team who will make arrangements for you.

# 7. Preference Forms

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## 1. MY LIST FOR LIVING



**Five things I would like to do:**

1. ....

2. ....

3. ....

4. ....

5. ....

**Five things I am proud I have done!**

1. ....

2. ....

3. ....

4. ....

5. ....

**People I want to spend time with, reconnect with or relationships I want to improve:**

1. ....

2. ....

3. ....

4. ....

5. ....



## 2. MY ADVANCE WISHES FOR CARE



This is a non-legally binding document to represent your future hopes and wishes. It has been adapted from the National Preferred Priorities for Care document.

Please copy this document for GP/district nursing notes and palliative care notes.

Ideally, you should keep this document with you and share it with anyone involved in your care.

### YOUR DETAILS

Name .....

Date of Birth .....

Address .....

..... Postcode .....

**Have you appointed a Lasting Power of Attorney (LPA)?** Yes  No

Is this for:

1. Health and Welfare LPA Yes  No

2. Property and Financial Affairs LPA Yes  No

3. Both Yes  No

Name of LPA .....

**Do you have an Advance Decision to Refuse Treatment Document?** Yes  No

### NEXT OF KIN (or other appointed decision-maker)

Please specify who else you would like to be involved if it ever becomes difficult for you to make decisions? If you have appointed an LPA then include their contact details here:

#### Contact 1

Name .....

Relationship to you .....

Telephone .....

Do they have Health and Welfare LPA? Yes  No

**Contact 2**

Name .....

Relationship to you .....

Telephone .....

Do they have Health and Welfare LPA? Yes  No

**Do you have any special requests or preferences regarding your future care?**

.....  
.....

**Where would you most like to be cared for at the end of your life?** (sometimes referred to as your preferred place of death)

.....  
.....

**How would you want your last days to look and sound? Who would you want with you?**

.....  
.....

**Are there any specific practices (religious or other) that are important to you at the time of death or shortly afterwards?**

.....  
.....

**Do you have any other comments or wishes you would like to share?**

.....  
.....

**I give permission for this document to be discussed with my relatives/carers:**

Yes  No  (please tick appropriate box)

**I agree to the information in this document being shared with relevant healthcare professionals via secure fax, electronically or paper copy:**

Yes  No  (please tick appropriate box)

Patient signature ..... Date .....

Next of kin/carer signature (if present) ..... Date .....

Healthcare professional signature ..... Date .....

**Details of other family members involved in advance care planning discussions**

Name .....

Address .....

Contact .....

**Details of healthcare professionals involved in advance care planning discussions**

Name .....

Address .....

Contact .....

Reviewed on (give dates): .....

**Remember to regularly review this document to ensure it still represents your wishes. Sign and date any changes you make.**





### 3. HOW I WANT MY LIFE TO BE CELEBRATED / REMEMBERED AFTER MY DEATH



**Do you have a preferred Funeral Director?** Yes  No

If yes, who? .....

**Do you already have a pre-paid funeral plan?** Yes  No

If yes, who with? .....

**Do you have any specific wishes regarding what happens to your body after you have died? (e.g. burial or cremation?)**

.....

**Do you have any religious views or needs that influence what you want to happen?**

.....

**Planning for your funeral or remembrance event:** (leave blank if this is not applicable)

Where should it ideally be held?.....

Who would be there?.....

Who might lead the event?.....

**Are there any particularly significant music, poems or readings you would want?**

.....

.....

**Do you have any requests for flowers, dress code or donations?**

.....

.....

**Any other general thoughts or wishes:**

.....

.....



## 4. PUTTING YOUR AFFAIRS IN ORDER – A CHECKLIST



Ensuring that your paperwork and documents are up to date and easy to find will help reduce anxiety for you, your family and / or next of kin.

Use the checklist below as a reminder that you have thought about and recorded in a safe place, the details listed.

Name: .....

|                             | Details and location of documents |
|-----------------------------|-----------------------------------|
| Bank Name and accounts      |                                   |
| Insurance policies          |                                   |
| Credit cards                |                                   |
| Pension                     |                                   |
| Passport                    |                                   |
| Birth/marriage certificates |                                   |
| Mortgage                    |                                   |
| Hire purchase agreements    |                                   |
| Will                        |                                   |

Other important documents/contacts

For example:

- Your Solicitor
- Details of any funeral arrangements or preferences
- Addresses and contact numbers of family, friends and colleagues.

**Whilst we do not advise you to include them here, you might like to keep a list of all your passwords for online accounts, mobile telephones and tablets and share them with a trusted individual. This may help when closing accounts or switching ownership at a later date.**



## 5. MY ADVANCE DECISION TO REFUSE TREATMENT (LIVING WILL)



This form enables you to write an Advance Decision to Refuse Treatment (ADRT) or 'living will'. Once completed, it allows you to legally refuse certain treatments. This is a formal procedure which is likely to be relevant to only a small minority of people. However for some people it is very important to have a legal document which refuses treatment in specific situations.

If this is something you want to go ahead with then you should discuss it and write it with a healthcare professional who is fully aware of your medical history.

**Remember** - you cannot make an advance decision to request medical treatment, or to have life ended. You can only say what treatment(s) you would refuse.

If you wish to include situations in which you would refuse life-sustaining treatment, the advance decision must be in writing (it can be written on your behalf), and must be signed by the maker in the presence of a witness, who must also sign the document. It must also be verified by a specific statement within the document that states the advance decision is to apply to the specified treatment even if life is at risk.

At the time of making this advance decision to refuse treatment you must:

- Be 18 years or over
- Be mentally competent and not suffering from any kind of mental distress
- Not have been influenced or harassed by anyone else
- Appear to be fully informed about the treatment options and their implications when the statement was written

It is important you are as specific as you can be about the situations in which you would be refusing treatment. Where doubt exists for the doctor as to whether the particular situation was the one that was anticipated, then the advance decision would not be considered applicable.

**An ADRT will only become active once you are unable to be involved in the decision-making process yourself.**

**A healthcare professional reading this document will consider the following:**

1. Has the person lost capacity to make decisions? Could the person be encouraged to participate in decision-making by use of any communication aids, a translator or their carer, for example.
2. If the person has lost capacity and cannot participate in decision-making, the healthcare professional will decide whether what is written is valid and applicable in the situation.

**This document would become invalid if:**

- You had subsequently said or written that this was no longer your wish
- A personal Health and Welfare LPA has been appointed. In this instance the Power of Attorney would make any healthcare decisions taking into account your wishes.
- You had done something clearly inconsistent with the advance decision, for example, requested intravenous antibiotics when you had declined antibiotics in the ADRT.

**Do remember that you can always change your mind about any decisions you make. We encourage you to regularly review the decisions you have made to ensure that these continue to represent your wishes.**

Name .....

Address .....

.....

Postcode: ..... Date of Birth.....

**What is this document for?**

This Advance Decision to Refuse Treatment (ADRT) has been written by me to specify in advance which treatments I do not want in the future. These are my decisions about my healthcare and should be referred to in the event that I have lost mental capacity and cannot consent to or refuse treatment. This ADRT replaces any previous advance decision I have made

**Advice to the reader:**

I have written this document to identify my ADRT. I would expect my healthcare professionals reading this document in the event that I have lost capacity to check that my advance decision is valid and applicable, in the circumstances that exist at the time.

**Please check:**

Please do not assume that I have lost capacity before any actions are taken. I might need help and time to communicate.

This ADRT becomes legally binding and must be followed if professionals are satisfied it is valid and applicable.

If I have appointed a Health and Welfare LPA then they are the appointed decision-maker.

**If applicable:**

Name of Health and Welfare LPA: .....

Address: .....

..... Postcode: .....

Home telephone: ..... Mobile telephone: .....

Email: .....

I am writing this at a time when I am able to think things through clearly and I have carefully considered my situation.

I am over 18 years old and am writing this of my own free will.

| I wish to refuse the following specific treatments | In these circumstances |
|--|------------------------|
|  |                        |
|  |                        |
|  |                        |
|  |                        |

**Examples:**

I do not want to receive intravenous antibiotics for a particular infection (state what), or

I do not wish to have a feeding tube inserted if I am unable to swallow

This ADRT applies to the specific treatments listed above, even if my life is at risk.

Signature ..... Date .....



Witness Name .....

Witness Signature ..... Date .....

Witness Address .....

.....

Postcode: ..... Witness Telephone .....

**I have discussed this ADRT with:**

GP  Dr.....

Nurse  .....

Hospice / Hospital Doctor  Dr.....

Solicitor  .....

Family / next of kin  .....

**I give permission for this document to be discussed with my relatives/carers:**

Yes  No  (please tick appropriate box)

**I agree to the information in this document being shared with relevant healthcare professionals via secure fax, electronically or paper copy:**

Yes  No  (please tick appropriate box)

My General Practitioner is Dr.....

Surgery Name and contact number: .....

**Optional Review**

This directive was reviewed and confirmed by me as still representing my wishes

Signed ..... Date .....

Witness Signature .....



# Notes

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**This booklet has been produced by Weston Hospicecare for use by patients of Weston Hospicecare, St. Peter's Hospice and the North Somerset Clinical Commissioning Group**

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