

# PLANNING AHEAD

## A LEAFLET FOR PATIENTS AND THEIR CARERS

These leaflets have been put together by professionals working in palliative care and are designed to help you think ahead and to practically help you make any arrangements or decisions in advance of a crisis.

We would recommend that you talk through the issues raised with a friend, family, doctor or palliative care nurse. This will help you to be clear in your decision-making and helps ensure family and professionals are more aware of your wishes and concerns.

We have found that the most useful part of the whole process is having the discussions about the future. The forms at the back of each section are for you to use if you wish. The completion of the forms should not become a goal in themselves.

There may be certain parts that are more relevant at any one time, however it may be appropriate to come back to the other sections at a later date.

### SEPARATE LEAFLETS ARE AVAILABLE ON THE FOLLOWING

- 1 Preferred Priorities for Care - your advanced wishes
- 2 Putting your affairs in order and making a will
- 3 Appointing someone to make decisions for you in the future
- 4 Writing an advance decision

These do not need to be worked through as an exercise. The preferred priorities for care is a very useful basic document which we would encourage as many people as possible to complete. This gives everyone an overview of your wishes for how you would like to be cared for.

Appointing someone to make decisions for you (a lasting power of attorney) or writing an advance decision is something which is likely to be appropriate for only a minority of people. These are legal processes and documents and it may be helpful for you to know they exist and to talk through in detail with your specialist palliative care nurse or doctor about whether this is something which would be useful for you.

#### **Key references/useful websites**

[www.endoflifecareforadults.nhs.uk/eolc/current/CS310.htm](http://www.endoflifecareforadults.nhs.uk/eolc/current/CS310.htm)

[www.dca.gov.uk/menincap/legis.htm](http://www.dca.gov.uk/menincap/legis.htm)      [www.mnd.MNDassociation.org](http://www.mnd.MNDassociation.org)

[www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)      [westonhospicecare.org.uk](http://westonhospicecare.org.uk)

# 1 PREFERRED PRIORITIES FOR CARE YOUR ADVANCED WISHES

(Adapted from National PPC document)

## WHAT IS THIS DOCUMENT FOR?

The Preferred Priorities for Care (PPC) can help you prepare for the future. It gives you the opportunity to think about, talk about and write down your preferences and priorities for care at the end of your life. You do not need to do this unless you want to.

The PPC can help you and your carers ( your family, friends and professionals) to understand what is important to you when planning your care. If a time comes when, for whatever reason , you are unable to make a decision for yourself, anyone who has to make decisions about your care on your behalf will have to take into account anything you have written in your PPC.

Sometimes people wish to refuse specific medical treatments in advance. The PPC is not meant to be used for such legally binding refusals. There is a separate leaflet about this called 'Advance Decisions to Refuse Treatment' it would be advisable to discuss this with your doctors if this is something you wish to pursue.

You may find that your feelings about your care change over time. This is entirely normal and simply reflects that different things become more or less important at different times, and that we do not always cope or respond as we expect in a given situation. You should ensure that any plans you make are kept as up to date as possible.

## SHOULD I TALK TO OTHER PEOPLE ABOUT MY PPC?

You may find it helpful to talk about your future care with your family and friends, although sometimes this can be difficult because it might be emotional or people might not agree. Often just having this discussion can be very useful, just to get these difficult issues out in the open. It may be helpful to talk about any particular needs your family or friends may have if they are going to be involved in caring for you. Your professional carers (like your doctor, nurse or social worker) can help and support your family with this.

## WILL MY PREFERENCES AND PRIORITIES BE MET?

What you have written in your PPC will always be taken into account when planning care. However, sometimes things can change unexpectedly (like carers becoming over-tired or ill) or resources may not be available to meet a particular need.

WHAT SHOULD I INCLUDE IN MY PPC?

Some things you may wish to consider:

**Where you think you would like to be cared for if you are dying?**

(Hospital, nursing home, hospice, at home).

Remember that you may find that when the time comes your preferred place of care may not be an option due to eg level of nursing required, lack of beds, need for hospital tests etc. or you may have changed your mind as to what is most suitable. However, this should not stop you considering your preferred care place.

**Whether you would want to be told when you are close to death**

(assuming your doctors are able to predict this), and whether you want other people to know.

**Who should talk to any children, or other close family such as elderly parents, about your impending death if you are unable to do so?**

**Who should look after your pets?**

**How you want your final days to look and sound?**

(flowers, pictures, photos, music, TV, radio etc)

**Who you would wish to visit you near the end?**

**Is there anything that you would not want to happen to you?**

(For example being admitted to hospital, being told you are dying etc)

**Organ Donation/Medical research**

Would you want to donate certain organs eg. corneas or to consider donating organs for medical research?

You will need to sign specific documentation for this.

There is a preferred priorities of care form attached which you may wish to complete and share with family and the healthcare professionals looking after you.

Some people find it helpful to record some thoughts and wishes around funeral arrangements too. There is a form covering details of funeral planning included as part of this information pack.

If you would like to discuss this further with a member of the hospice team, this can be arranged by contacting us.

# PREFERRED PRIORITIES FOR CARE DOCUMENT

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

Please copy for GP/ district nursing notes and palliative care notes.  
Ideally keep this document with you and share it with anyone involved in your care.

Your Name .....

Address .....

..... Postcode .....

**Do you have a Living Will or Legal Advanced Decision?** Yes / No

If yes please give details (who has a copy?) .....

.....

## PROXY / NEXT OF KIN

**Who else would you like to be involved if it ever becomes difficult to make decisions?**

Contact 1 ..... Relationship to you .....

Telephone ..... Do they have Lasting Power of Attorney Yes / No

Contact 2 ..... Relationship to you .....

Telephone ..... Do they have Lasting Power of Attorney Yes / No

**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?**

**Is there any thing you would ideally like to avoid happening to you?**

**Do you have any comments or wishes that you would like to share with others?**

**Are you happy for the information in this document to be shared with other relevant healthcare professionals? Yes/No**

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

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

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

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

Details of healthcare professionals involved in advance care planning discussions

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

.....

.....

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

# 2 PUTTING YOUR AFFAIRS IN ORDER AND MAKING A WILL

It is worth asking yourself, how easy is it for my next of kin to find all my important documents if I become ill, or die suddenly. How can I make it easier for them?

This will save your family having to search through piles of paper to find the information they need, at a time of great stress. The instructions could include:

- Details of you bank, building society, credit cards, pension, tax district and any other financial contacts

- Telephone numbers and addresses of close (and distant) friends, family and colleagues

- Where you keep documents eg passport, house deeds, insurance, life and other policies, mortgage and hire purchase agreements, birth and marriage certificates.

There is a form attached which you may find useful to use to start documenting some of this practical information. We suggest this is kept in a safe place.

There is also a check-list form to help when considering funeral plans. It can be helpful to discuss your thoughts with your faith leader, the hospice or hospital chaplain or a funeral director. Weston Hospice has a leaflet specifically on funeral planning to help you in your thinking about the options for both religious and non-religious services.

## WRITING A WILL

Dying without leaving a will may cause problems for your relatives, often needing lawyers to sort them out. A do-it-yourself will form bought via a stationers or via the internet can be fine for straightforward situations, but bear in mind that a will is a technical and legal document and mistakes cannot be corrected after your death. 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 by 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 about arrangements for the care of pets or other responsibilities.

# PUTTING YOUR AFFAIRS IN ORDER CHECK LIST

Information you may wish to start putting together.

**Please keep this document somewhere safe**

	Details	Place kept
Bank Name Account details		
Insurance policies		
Credit cards		
Pension		
Passport		
Birth/marriage certificates		
Mortgage		
Hire purchase agreements		
Will		
Other important documents/contacts eg Solicitor		

# FUNERAL PLANNING

	<b>Details</b>
Person I wish to be responsible for making my funeral arrangements	
My preferred funeral director is	
My pre-paid funeral plan is with	
I wish to be buried / cremated	
I wish my funeral service to be at	
My wishes for music to be included in the service are	
I would like the following 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 eg donations to named charity, flowers, people to be informed	

# 3 APPOINTING SOMEONE TO MAKE DECISIONS FOR YOU IN THE FUTURE

If you become unable to participate in decision-making at any point, we as healthcare professionals will do everything possible to facilitate your participation (eg hearing aids, large print, use of interpreters etc). However if we feel you still do not have the ability to be involved in decision-making then a decision would be made considered to be in your best interests. Your next of kin and key carers as well as the multiprofessional healthcare team would all contribute to these discussions. For most people this way of making decisions is a good one.

In certain situations patients are able to anticipate that they will deteriorate mentally eg advancing alzheimers and will want to stipulate that a particular person can make decisions on their behalf when they are no longer able to do so. Such a person is given Lasting Power of Attorney (LPA).

The person that you choose can be a friend, relative or professional. You can choose more than one person to act as an attorney on your behalf. Your LPA is specific to you- you decide who will have the power to control your affairs and the precise limits of that power.

THERE ARE TWO TYPES OF LPA

**Property and affairs LPA** - such a person can make decisions about financial matters eg selling your house, or managing your bank account.

**A personal welfare LPA** - such a person(s) can make decisions about your health and personal welfare eg where you should live, day-to-day care or having medical treatment.

A personal welfare LPA will only take effect when you lack capacity to make decisions. With a property and affairs LPA the attorney can start managing the financial affairs as soon as the LPA is registered (when you may still have capacity) unless it is specifically stated that this should only happen after you lose capacity.

Forms are available from the Office of the Public Guardian.

The application has to be registered with the Office of the Public Guardian in order to be valid. Appointing such an attorney can be done without a solicitor but the process is quite complex, but do remember that engaging a solicitor may incur significant cost.

# 4 WRITING AN ADVANCE DECISION (LIVING WILL)

You may have heard of an advance decision or living will. Such a document can allow 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 specifically refuses treatment in specific situations as this would not be acceptable to them.

An advance decision has to be very specific in order to be useful. For example: patients who have motor neurone disease can anticipate that swallowing will become a problem as part of the progression of the disease and for some patients the insertion of a feeding tube might be completely unacceptable and this could be formally documented as an advance decision.

You cannot make an advance decision to ask for medical treatment, or to have life ended. You can only say what types of treatment you would refuse. The Mental Capacity Act (2005) addresses issues that can affect anyone unable to make some or all of their own decisions and gives them increased legal rights. This has given advance decisions a legal status.

There is no specific format to follow to make an advance decision. It can be verbal or written. However, 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 the patient's 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.

If this is something you wish to consider then you should discuss it with a member of the palliative care team or your GP. It may be that expressing your wishes to your family and healthcare professionals is sufficient.

If you decide, after discussion with the palliative care team / GP that you do want to proceed with an advance decision document then we would recommend that you discuss this with at least one of the doctors who are looking after you; this may be your General Practitioner, your palliative care consultant, medical consultant etc. It may also be appropriate for you to ask a solicitor to be involved.

#### AT THE TIME YOU MAKE AN ADVANCE DECISION YOU MUST BE

Aged 18 or over

Mentally competent and not suffering from any kind of mental distress at the time it is drawn up

Must not have been influenced or harassed by anyone else

Must appear to be fully informed about the treatment options and their implication when the statement was written

Must not have modified the advance directive verbally or in writing since it was signed and dated

In considering making an advance decision there are some treatments you may wish to consider whether (if offered) you would find acceptable

#### RESUSCITATION

Cardio-pulmonary resuscitation (CPR) is just one of a range of active interventions which you may wish to consider.

In patients who are generally weak, who are gradually deteriorating and in whom there are a number of medical problems, then the chance of resuscitation being successful is extremely low (<1%). Given the low chance of success in these situations then doctors will sometimes decide that offering resuscitation is inappropriate as it would be extremely unlikely to lead to a return to a reasonable quality of life. It may also be felt that discussing this, when it is not likely to be successful, may simply add to distress.

Where there is a possibility that resuscitation may be successful then it will be discussed with you.

If this has not been discussed with you and you would like to do so, then ask either your hospice nurse or doctor, or your own GP.

#### OTHER ACTIVE INTERVENTIONS

For patients with motor neurone disease then it may be appropriate to consider whether tube feeding (via a PEG), or any form of ventilatory support would be acceptable. These decisions are not straightforward and should be fully discussed with your family and medical team. Information is available from the MND association ([www.MNDassociation.org](http://www.MNDassociation.org)) where there are useful fact sheets on swallowing and breathing difficulties, which may be experienced in motor neuron disease patients and the pros and cons of the different approaches.

Other treatments which you may wish to consider include the use of intravenous antibiotics, stent insertion, nasogastric feeding. Some of these treatments may be offered to help control distressing symptoms and not simply 'to prolong life'. If not giving any of these treatments might threaten life, then you need to have made it clear that you would not want the specified treatments even though life is at risk.

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

There is an advance decision document attached if this is something you feel is appropriate for you. As mentioned please complete it alongside discussions with your palliative care doctors and nurses as well as your GP.

# ADVANCE DECISION DOCUMENT

## You will need 4 copies of this completed form

- One for you to keep
- One for your GP to keep with your records
- One to be kept with someone who you wish to be consulted about your treatment should this ever be necessary. (eg next of kin, solicitor)
- One to be kept with Palliative Care Team  
Community palliative Care nurse/ hospice team

Please also ask the healthcare team to fax a copy to the Ambulance Service so that they can update their alert system, particularly relating to any refusal of resuscitation.

**Fax No. 0845-1204340**

All forms should be signed by at least one person, who is not a close relative or expecting to benefit from your will. (eg GP, or hospice/ hospital doctor).

You might also wish to consult with your solicitor.

Remember to review this document at regular intervals 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, hospice nurse, next of kin or appointed representative and amend the document accordingly.

## PROXY /NEXT OF KIN

**Who else would you like to be involved if it ever becomes too difficult to make decisions? Do they have Lasting Power of Attorney (LPA) to make decisions on your behalf relating to treatment?**

- Contact 1 ..... Relationship to you  
Telephone ..... Do they have Lasting Power of Attorney Yes / No
- Contact 2 ..... Relationship to you  
Telephone ..... Do they have Lasting Power of Attorney Yes / No

To my family, my doctor and all other persons concerned this directive is made by me:

Full name.....

Of (address).....

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 aware that I have been diagnosed as suffering from:

- Advanced and widespread cancer
- Advanced degenerative disease of the nervous system (eg motor neurone disease)
- Advanced and irreversible organ failure (eg severe heart failure, renal failure, dementia, COPD) or other progressive chronic condition. Please state diagnosis:

I declare that if I become unable to participate effectively in decisions about my medical care, then and in those circumstances, my directions are as follows:  
(only sign the sections you feel are applicable).

- 1.** I am not to be subjected to any medical intervention or treatment aimed solely at prolonging my life.

Signature .....

- 2.** Any distressing symptoms (including those caused by lack of food or fluids) are to be fully controlled by appropriate analgesic, sedative or other treatment, even though that treatment may shorten my life.

Signature .....

- 3.** This advance decision applies to the specific treatments stated below, even if my life is at risk.

Signature .....

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

<b>Treatment to be refused</b> (eg resuscitation, stoma formation, surgery)	<b>Details of situation you have anticipated in which the refusal would be valid</b> (eg <b>1</b> for resuscitation - details might be: in the attempt of sudden collapse I would not want resuscitation either at home or in an ambulance or in hospital. eg <b>2</b> refusal of PEG- details if unable to swallow. eg <b>3</b> use of antibiotics in the situation of developing a chest infection. eg <b>4</b> re-insertion of a stent- if it blocks. eg <b>5</b> placing of a nasogastric tube if the bowel is blocked, etc)

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions.

I reserve the right to revoke this directive at any time, but unless I do so it should be taken to represent my continuing directions

My General Practitioner is:

Name of GP .....

Address .....

Telephone .....

Before signing this I have talked it over with my :

- GP Dr .....
- Hospice Nurse .....
- Hospice Consultant/ Hospital Doctor Dr .....
- Solicitor .....

(it is recommended that you discuss this with at least one of the above professionals. If you are in hospital or hospice then the consultant caring for you should be aware of and clear about the scope of this advance decision).

I have attached a sheet with further wishes about my treatment. Yes/No

**Are you happy for the information in this document to be shared with other relevant healthcare professionals?** Yes/No

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

Witnesses:

We testify that the maker of this advance directive signed it in our presence, and made it clear to us that he/she understood what it meant. We do not know of any pressure being brought on him/ her to make such a directive and we believe it was made by his/ her own wish. So far as we are aware we do not stand to gain from his/ her death.

Only one witness is legally required.

Witnessed by:

**Witness 1** (Ideally GP, or Hospice Doctor, Hospital doctor)

**Witness 2** (not close family, or persons expecting to benefit from your will)

Signature .....

Signature .....

Date .....

Date .....

Name .....

Name .....

Address .....

Address .....

**Reviews** This directive was reviewed and confirmed by me on:

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

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