PLANNING AHEAD

A RESOURCE FOR PATIENTS AND THEIR CARERS

This document has been reviewed and agreed upon by health care professionals and users involved in end of life care strategic development in East Sussex. We are grateful for Weston Hospice care for their permission to adapt their original documents.

This document is designed to help you think ahead and make any practical arrangements or decisions in advance of a crisis.

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

For some, a useful part of the whole process is to have a discussion about the future. There may be certain areas of discussion about the future that are more relevant at any one time. It may be appropriate to come back to the other sections at a later date.

This document is formed of four sections. At the back of each section are forms that you can use if you so wish. Do not worry if you do not feel like completing a form; you may decide that having an open discussion is enough for you and you do not wish to put anything in writing. The sections are:

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 (to refuse a treatment).

The 'preferred priorities for care' can be very useful as it ensures that everyone has 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 (LPA) or writing an advance decision is something which is likely to be appropriate for only a few people. These involve legal processes and documents. It may be helpful to know they exist and to talk through them with an appropriate professional involved in your care to see if they would be useful for you.

Key references/useful websites

www.endoflifecareforadults.nhs.uk/eolc/current/CS310.htm
www.ADRTNHS.co.uk
www.goldstandardsframework.nhs.uk
www.stwhospice.org

1 PREFERRED PRIORITIES FOR CARE (PPC) YOUR ADVANCE WISHES

(Adapted from National PPC document)

WHAT IS THIS DOCUMENT FOR?

The Preferred Priorities for Care (PPC) section can help you prepare for the future. It gives you the opportunity to think about, discuss 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 future 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 the care you receive, on your behalf, will be able 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 is advisable to discuss this with your doctor or specialist team if this is something you wish to pursue.

You may find your feelings about your care change over time. This is entirely normal. It simply reflects that different things become more or less important at different times, and that we cannot always respond as we would hope to in a given situation. You should ensure 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 someone close to you such as family or friends. However, this can sometimes be difficult as people might not agree or it might be too emotional. Often, just having a discussion can be very useful, in order to get difficult issues out into 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 (for example your doctor, nurse or social worker) can help and support you and 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 (for example carers becoming over-tired or ill) or practical resources not being available to meet a particular need.

WHAT SHOULD I INCLUDE IN MY PPC?

Things you may wish to consider:

Where do you think you would like to be cared for if you are dying
(for example home, hospital, nursing home, hospice)?

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

Whether you would want to be told when you are close to death
(assuming your doctors and nurses 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 (for example 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, having investigations)?

Tissue Donation/Medical research
Would you want to donate certain tissues after you die? Even after a natural, dignified death, certain tissues can be beneficial to others, for example parts of the eye such as the corneas. You may feel strongly about wanting to donate 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 look at and 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. A form covering details of funeral planning is included as part of this information pack.

If you would like to discuss this further with a member of the team involved in looking after you, please just ask.

PREFERRED PRIORITIES FOR CARE DOCUMENT

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

Ideally keep this document with you and share it with anyone involved in your care. A copy will be needed for GP/ district nursing / hospice / MacMillan / nursing home notes as appropriate-

Your Name .....

Address .....

..... Postcode .....

Do you have a 'Living Will' or Legal Advance Decision? Yes / No
If yes please give details (who has a copy?) .....

.....

PROXY / NEXT OF KIN

i.e. 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 your 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, e.g. 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 (if involved) or a funeral director.

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 form, for completing a will, bought via a stationers or via the internet can be fine for straightforward situations, but bear in mind 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 e.g. solicitor		

FUNERAL PLANNING

	Details
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, e.g. 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 (e.g. hearing aids, large print, use of interpreters). However, if we feel you still do not have the ability to be involved in decision-making, then a decision would need to be made that was considered to be in your 'best interests'. Your next of kin and other key carers, as well as the multi-professional healthcare team would all help 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 may deteriorate mentally, for example. advancing dementia. In cases such as these you may want to stipulate that a particular person can make decisions on your behalf, if you are no longer able to do so. Such a person is given Lasting Power of Attorney (LPA).The person 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

- **A property and affairs LPA** - such a person can make decisions about financial matters e.g. 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 e.g. where you should live, day-to-day care or having medical treatment.

A personal welfare LPA will only take effect when you lack the capacity to make decisions. With a property and affairs LPA, the attorney can start managing financial affairs as soon as the LPA is registered (when you may still have capacity), unless it is specifically stated 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. Although appointing such an attorney can be done without a solicitor, the process can be quite complex to do on your own. However, remember that engaging a solicitor may incur costs.

Useful Website: http://www.publicguardian.gov.uk/

4 WRITING AN ADVANCE DECISION

You may have heard of an advance decision (or the older term, 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 few people. However, for some people, it is very important to have a legal document which specifically allows them to refuse treatment in certain 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 neuron 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. 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 decision 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 the most appropriate healthcare professional (i.e. the professional who knows you and your condition well and can spend time with you assisting this process). It may be that expressing your wishes to your family and healthcare professionals is sufficient.

If you decide after your discussion 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 GP, your palliative care (hospice) 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 decision 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 (less than 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 any specialist nurse or doctor involved in your care, including your own GP.

OTHER ACTIVE INTERVENTIONS
For patients with neurological conditions, e.g. 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 Motor Neurone Disease Association (www.MNDassociation.org) where there are useful fact sheets on swallowing and breathing difficulties, which may be experienced in motor neurone disease patients and the pros and cons of the different approaches.

Other treatments relevant to your condition (e.g. cancers or advanced stages of heart or lung conditions) which you may wish to consider include the use of intravenous antibiotics, stent insertion and 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 any specialist nurse or doctor involved in your care, as well as your GP. The advance decision needs to be specific to you and your health problems.

ADVANCE DECISION DOCUMENT

You will need at least 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. (e.g. next of kin, solicitor)
- Others for healthcare professionals involved in your care such as hospice staff / MacMillan nurse specialists or nursing / care home managers and the local acute hospital.

Please also ask the healthcare team to fax a copy to the ambulance service and 'out-of-hours' medical service so that they can update their alert system, particularly relating to any refusal of resuscitation.

All forms should be signed by at least one person, who is not a close relative or expecting to benefit from your will (e.g. 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 or MacMillan 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 (e.g. motor neurone disease)
☐ Advanced and irreversible organ failure (e.g. severe heart failure, renal failure, dementia, COPD) or other progressive chronic condition. Please state diagnosis:
☐ Other

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.

Treatment to be refused (e.g. resuscitation, stoma formation, surgery, IV antibiotics)	**Details of situation you have anticipated in which the refusal would be valid** (Example 1 resuscitation - details might be in the event of cardiac arrest I would not want resuscitation either at home or in an ambulance or in hospital. Example 2 refusal of PEG - details if unable to swallow. Example 3 use of antibiotics in the situation of developing a chest infection. Example 4 re-insertion of a stent- if it blocks. Example 5 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 advance decision 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 or MacMillan Nurse ……

☐ Hospice Consultant/ Hospital Doctor Dr ……

☐ Solicitor ……

It is recommended 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 person making this advance decision 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 an advance decision 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)

Signature ……

Date ……

Name ……

Address ……

……

Witness 1 (not close family, or person expecting to benefit from your will)

Signature ……

Date ……

Name ……

Address ……

……

Reviews This directive was reviewed and confirmed by me on:

Date …… Signed ……

Date …… Signed ……